

Child Family Survey

Final Report – January 2004
2002-2003 Data



A Collaboration of
National Association of State Directors of Developmental Disabilities Services and
Human Services Research Institute

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January 2004

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Organization of Report

Six states and one local developmental disability authority conducted the National Core Indicators (NCI) Child Family Survey during the 2002-2003 project year and submitted data. The Child Family Survey was administered to families having a child with disabilities living in the family's home. This Preliminary Report provides a summary of results, based on the data submitted by June 2003.

This report is organized as follows:

I. INTRODUCTION

This section provides an overview of the National Core Indicators, and a brief history of the development, administration, and participation of states in the NCI Child Family Survey.

II. CHILD FAMILY SURVEY

This section briefly describes the structure of the survey instrument.

III. METHODS

This section illustrates the protocol used by states to sample participating families, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by Human Services Research Institute staff to aggregate and analyze the data.

IV. RESULTS

This section provides aggregate and state-by-state results for demographic, service utilization, service access and delivery, satisfaction and outcome data.

V. DISCUSSION OF RESULTS

This section provides aggregate and state-by-state results for demographic, service utilization, service planning, access and delivery, choice and control, community connections, satisfaction and outcome data. It also provides an overall view of the aggregate survey results.

I. Introduction

Overview of National Core Indicators

In 1996, the NASDDDS Board of Directors launched the Core Indicators Project (CIP). The project's aim is to support state developmental disabilities authorities (SDDAs) in developing and implementing performance/outcome indicators and related data collection strategies that will enable them to measure service delivery system performance. The project strives to provide SDDAs with sound tools in support of their efforts to improve system performance and thereby to better serve people with developmental disabilities and their families. NASDDDS' active sponsorship of CIP facilitates states pooling their knowledge, expertise and resources in this endeavor.

Phase I – Phase I of CIP began in 1997 when the CIP Steering Committee selected a “candidate” set of 61 performance/outcome indicators (focusing on the adult service system), in order to test their utility/feasibility. Seven states agreed to conduct a field test of these indicators, including administering the project's consumer and family surveys and compiling other data. Field test data were transmitted to project staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

1999 - 2000 – Phase II of CIP was launched in 1999, with a deadline for collection of 1999 data set in June 2000. During Phase II, the original indicators were revised and data collection tools and methods were improved. The new (Version 2.0) indicator set consisted of 60 performance and outcome indicators. Twelve states (Arizona, Connecticut, Kentucky, Massachusetts, Minnesota, Nebraska, North Carolina, Pennsylvania, Rhode Island, Virginia, Vermont, Washington) participated in Phase II, and this data is considered baseline project data. .

2000 - 2001 (Phase III) – In the spring and summer of 2001, data from the year 2000 was collected. At this time, it was decided to switch from describing the data sets as “phases” of the project to describing them by year in which the data was collected. Therefore, Phase III was now 2000 Data. Moving forward, four additional states joined the project (Delaware, Iowa, Montana, Utah) and the project expanded its scope to include services for children with developmental disabilities and their families. Also during this time, the CIP staff and participants continued to develop and refine the indicators, and recruit additional states to participate in the project. Technical reports for Phase II (1999 Data) and 2000 Data, along with other selected documents are available online at www.hsri.org/cip/core.html

2001 - 2002 (Phase IV) – The Core Indicators Project (CIP) officially changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. Participation in the National Core Indicators is entirely voluntary. For this year's round of data collection, seven new states and one local DD authority joined NCI (Alabama, Orange County in California, Hawaii, Illinois, Indiana, Oklahoma, West Virginia, Wyoming). During 2001-2002, 20 states and one local authority were active in NCI.

2002 – 2003 (Phase V) - Project participation continues to grow. During this past year, Maine, South Carolina and South Dakota have joined the National Core Indicators effort.

The figure on the following page summarizes state participation in the National Core Indicators since its inception through the 2002-2003 data collection cycles. States are listed if they participate in one or more of the NCI activities (e.g., consumer survey, family surveys, expenditure/utilization data, etc.).

Table 1 State Participation in National Core Indicators				
Phase I Field Test	Phase II 1999-2000	Phase III 2000-2001	Phase IV 2001-2002	Phase V 2002-2003
AZ	AZ	AZ	AL	AL
CT	CT	CT	AZ	AZ
MO	KY	DE	CA - Orange Co.	CA - Orange Co.
NE	MA	IA	CT	CT
PA	MN	KY	DE	DE
VT	NE	MA	HI	HI
VA	NC	MN	IL	IN
	PA	MT	IN	IA
	RI	NE	IA	KY
	VT	NC	KY	MA
	VA	PA	MA	ME
	WA	RI	NE	NE
		UT	NC	NC
		VT	OK	OK
		WA	PA	PA
			RI	RI
			UT	SC
			VT	SD
			WA	VT
			WV	WA
			WY	WV
				WY

Denotes first year of participation in NCI.

Family Indicators

Obtaining direct feedback from families is an important means for states to gauge satisfaction with services and supports as well as to pinpoint potential areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to gauge changes in performance over time. In addition, these results permit a state to compare its own performance against other states.

Previously, there were two family-related indicators under the **Consumer Outcomes** domain of the Phase II Core Indicators. The two sub-domains were **Supporting Families** and **Family Involvement**. From these sub-domains, three family surveys had been designed: the Adult Family Survey; the Children Family Survey; and the Family/Guardian Survey.

During this past year, new Family Indicators were developed and approved by the NCI Steering Committee. The table below details the new Sub-Domains, Concerns, and Indicators, and identifies the survey instruments in which the indicators are explored. The new Sub-Domains include: **Information and Planning, Choice and Control, Access and Support Delivery, Community Connections, Family Involvement, Satisfaction and Outcomes**. Each of the three family surveys follow, in structure, this new framework.

Table 2
Family Indicators

DOMAIN	FAMILY INDICATORS The project's family indicators concern how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.		
SUB-DOMAIN	CONCERN	INDICATOR	DATA SOURCE
Information & Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.	The proportion of families who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	All Surveys
		The proportion of families who report they have the information needed to skillfully plan for their services and supports.	All Surveys
		The proportion of families reporting that their support plan includes or reflects things that are important to them.	All Surveys
		The proportion of families who report that staff who assist with planning are knowledgeable and respectful.	All Surveys
Choice & Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.	The proportion of families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).	Children & Adult Family Surveys
		The proportion of families who report they choose, hire and manage their service/support providers.	All Surveys
		The proportion of families who report that staff are respectful of their choices and decisions.	All Surveys
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.	The proportion of eligible families who report having access to an adequate array of services and supports.	All Surveys
		The proportion of families who report that services/supports are available when needed, even in a crisis.	All Surveys
		The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication .	All Surveys
		The proportion of families who report that service and support staff/providers are available and capable of meeting family needs.	All Surveys
		The proportion of families who report that services/supports are flexible to meet their changing needs.	All Surveys
		The proportion of families who indicate that services/supports provided outside of the home (e.g., day/employment, residential services) are done so in a safe and healthy environment.	Both Adult Surveys
Community Connections	Families/family members use integrated community services and participate in everyday community activities.	The proportion of families/family members who participate in integrated activities in their communities.	All Surveys
		The proportion of families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	All Surveys
Family Involvement	Families maintain connections with family members not living at home.	The proportion of families/guardians of individuals not living at home who report the extent to which the system supports continuing family involvement.	Family/Guardian Survey
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	All Surveys
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Children & Adult Family Surveys

II. Child Family Survey

Background

This report focuses on the Child Family Survey.

2000 - 2001 – In the year 2000, five states participated and mailed out over 5,000 Child Family Surveys. Response rates among states ranged from 30% to 57%, with approximately 2,000 completed surveys returned.

2001 - 2002 – In the year 2001, four states and one local developmental disability authority participated and mailed out over 6,500 Child Family Surveys. Response rates among states ranged from 26% to 49%, with approximately 1,800 completed surveys returned.

2002 - 2003 – The results from this survey are explored, in detail, in this report.

State Participation

Below is a figure indicating state participation in the Child Family Survey since its inception.

Table 3 State Participation in NCI Children Family Survey (Children Living at Home)				
Phase I Field Test	Phase II 1999 Data	Phase III 2000 Data	Phase IV 2001 Data	Phase V 2002 Data
NA	NA	AZ MN NC UT WA	CA - Orange Co. NE NC UT VT	AZ CA - Orange Co. MA SC SD WA WY

Survey Instrument

States that administer the Child Family Survey agree to employ the NCI's base instrument and questions. If it wishes, a state may include additional questions to address topics not dealt with in the base instrument. Since all states use the standard questionnaire, the results are comparable state-to-state. Here, we describe the Child Family Survey developed. Further on in the report, we discuss how the surveys were administered and how the results were analyzed.

The Child Family Survey used in 2002-2003 not only asks families to express their overall level of satisfaction with services and supports, it also probes specific aspects of the service system's

capabilities and effectiveness. Along with demographic information, the survey includes questions related to: the exchange of information between individuals/families and the service system; the planning for services and supports; access and delivery of services and supports; connections with the community; and outcomes. Combined, this information provides an overall picture of family satisfaction within and across states.

Demographics – The survey instrument begins with a series of questions tied to characteristics of the child with disabilities (e.g., child's age, race, type of disability). It is then followed by a series of demographic questions pertaining to the respondent (e.g., respondent's age, health status, relationship to individual).

Services Received – A brief section of the survey asks respondents to identify the services and supports their family/child receives.

Service Planning, Delivery & Outcomes – The survey then contains several categories of questions that probe to specific areas of quality service provision (e.g., information and planning, access and delivery of services, community connections). Each question is constructed so that the respondent can select from three possible responses ("always or usually", "sometimes", and "seldom or never"). Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable for their family/family member.

Additional Comments – Finally, the survey provides an opportunity for respondents to make additional open-ended comments concerning their family's participation in the service system.

III. Methods

Sampling & Administration

States administered the Child Family Survey by selecting a random sample of 1,000 families who: a) have a child with developmental disabilities living at home, and b) receive service coordination and at least one additional service or support. Children were defined as individuals with disabilities under age 22. A sample size of 1,000 was selected in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. With 400 usable responses per state, the results may be compared across states within a confidence level of $\pm 10\%$. In states where there were fewer than 1,000 potential respondent families, surveys were sent to all eligible families.

Each state entered survey responses into a standard file format and sent the data file to HSRI for analysis. As necessary, HSRI personnel "cleaned" (i.e., excluded invalid responses) based on three criteria:

- ♦ The question "Does your child live at home with you?" was used to screen out respondents who received a survey by mistake. For instance, if a respondent indicated that their child with disabilities lived outside of the family home, yet received the Child Family Survey, their responses were dropped.
- ♦ If the respondent indicated that their family member was over the age of 21, their responses were dropped.
- ♦ If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

Response Rates

During the 2002-2003 data year, six states and one local developmental disability authority administered the Child Family Survey. Table 4 shows the number of surveys each state mailed out, the number and percent returned, and the number of valid surveys accepted for inclusion in data analysis.

Table 4			
Child Family Survey - State Response Rates			
State	Surveys Mailed	Surveys Returned (%)	Usable Surveys
Arizona	1,200	358 (30%)	347
CA-Orange Co.	4,501	923 (21%)	923
Massachusetts	1,500	378 (25%)	370
South Carolina	*	118 (*)	104
South Dakota	342	174 (51%)	171
Washington	1,500	490 (33%)	476
Wyoming	420	187 (45%)	187
Overall	*	1,299 (*)	2,231
* denotes data missing			

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. Once additional data is received, Table 4 indicates the response rates by state, based on the number of returned surveys entered into the database and submitted for analysis, compared to the total number mailed out.

Data Analysis

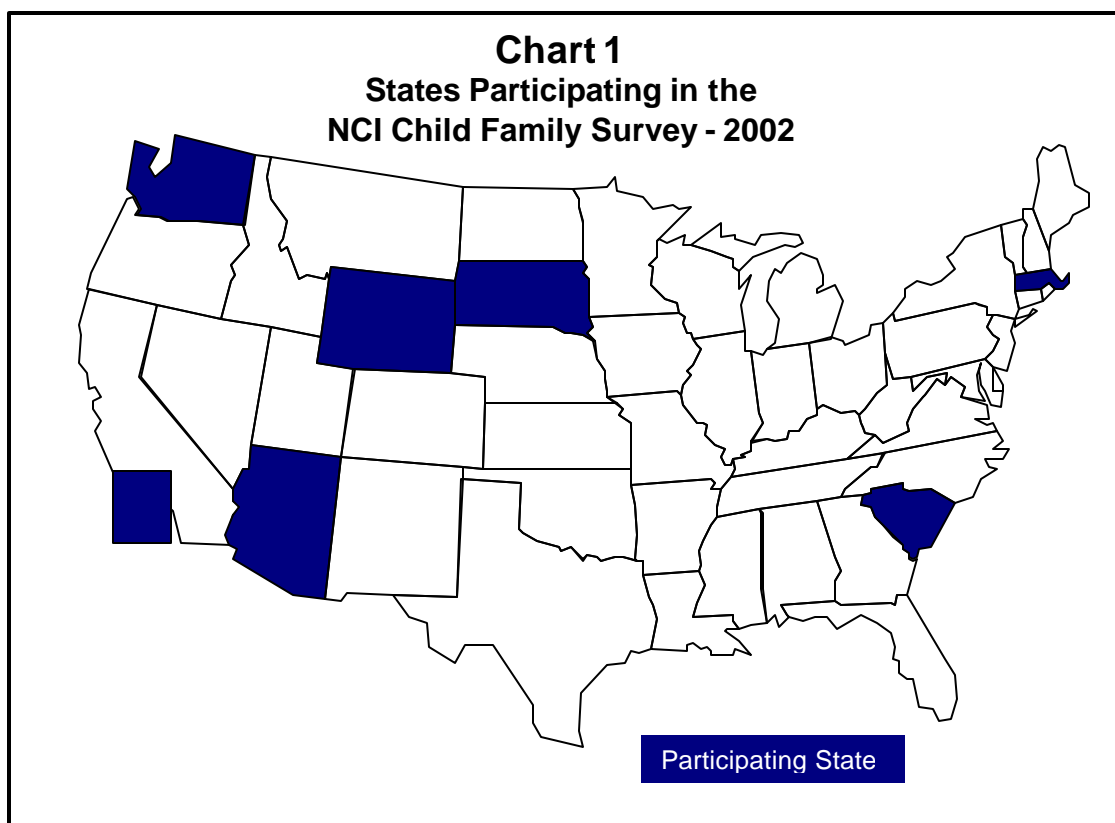
NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 10) software for statistical analysis and N6 software for support in analysis of open-ended comments.

IV. Results

The figures below provide the findings from the Child Family Survey. Findings are presented in aggregate, as well as by state.

Participating States

- ♦ Six states (Arizona, Massachusetts, South Carolina, South Dakota, Washington and Wyoming) and one local developmental disabilities authority (Orange County Regional Center in California) provided data for this Report.



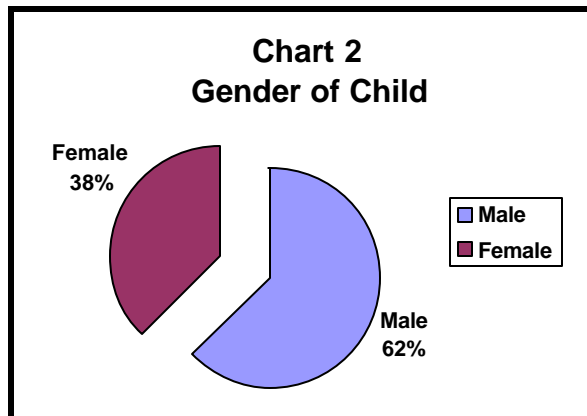
Characteristics of Children with Disabilities

This section provides information about the child with disabilities living in the household.

Gender of Family Member

- ♦ On average, across the states, 62% of children with disabilities were male, 38% were female.

Table 5 Gender		
State	% Male	% Female
AZ	64	36
CA-RCOC	68.9	31.1
MA	66.0	34.0
SC	59.6	40.4
SD	51.5	48.5
WA	61.6	38.4
WY	65.6	34.4
Total n	1,624	888
Total %	64.6	35.4
State Avg. %	62.5	37.5



Age of Family Member

- ♦ Across all participating states, the average age of children with disabilities was 9.4, with a range in age from 0 to 21.

Table 6 Age of Child		
State	Average Age	Range
AZ	7.7	1-21
CA-RCOC	9.2	0-19
MA	10.0	0-19
SC	7.1	1-17
SD	9.1	1-18
WA	10.5	1-18
WY	12.3	2-21
Total n	2,499	
Total Avg.	9.5	0-21
State Avg.	9.4	

Race of Family Member

In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.

- ♦ Across all states, 72% of the children with disabilities were White, 9% were Black/African-American, 4% were American Indian/Alaska Native, 4% were Asian-American, 1% were Native Hawaiian/Pacific Islander, 5% were Mixed Races, and 12% were Hispanic/Latino.

Table 7 Race/Ethnicity of Child (%)								
State	White	Black/ African American	Asian	American Indian/ Alaska Native	Native Hawaiian/ Pacific Islander	Mixed Races	Other/ Unknown	Hispanic/ Latino
AZ	55.5	6.4	3.5	9.5	0.3	7.8	0.3	24.6
CA-RCOC	43.7	1.9	14.7	2.0	0.9	6.1	1.0	36.8
MA	87.3	4.7	1.1	3.3	0.0	4.4	0.3	5.2
SC	57.9	40.8	2.1	1.0	3.1	4.1	4.1	5.2
SD	88.3	2.9	1.2	4.1	0.0	3.5	0.6	0.6
WA	77.4	5.2	6.0	4.7	1.5	5.8	1.3	7.3
WY	93.0	1.6	0.5	2.7	0.5	2.1	0.0	5.3
Total n	1,639	128	180	98	20	138	22	483
Total %	65.0	5.1	7.1	3.9	0.8	5.5	0.9	19.1
State Avg. %	71.9	9.1	4.2	3.9	0.9	4.8	1.1	12.1

More Than One Person with Disabilities Living in Household

- ♦ On average, 17% of households include more than one individual with a developmental disability. However, the range varied dramatically from 11% in South Dakota to 27% in Massachusetts.

Table 8		
More Than One Person in Household with a Developmental Disability		
State	% Yes	% No
AZ	17.8	82.2
CA-RCOC	15.0	85.0
MA	27.0	73.0
SC	12.6	87.4
SD	10.7	89.3
WA	23.9	76.1
WY	11.8	88.2
Total n	460	2,077
Total %	18.1	81.9
State Avg. %	17.0	83.0

Level of Mental Retardation of Family Member

- ♦ On average, 78% of children with disabilities required moderate to complete levels of assistance with activities of daily living. Fewer than one-quarter (22%0 of children required little or no assistance with these activities.

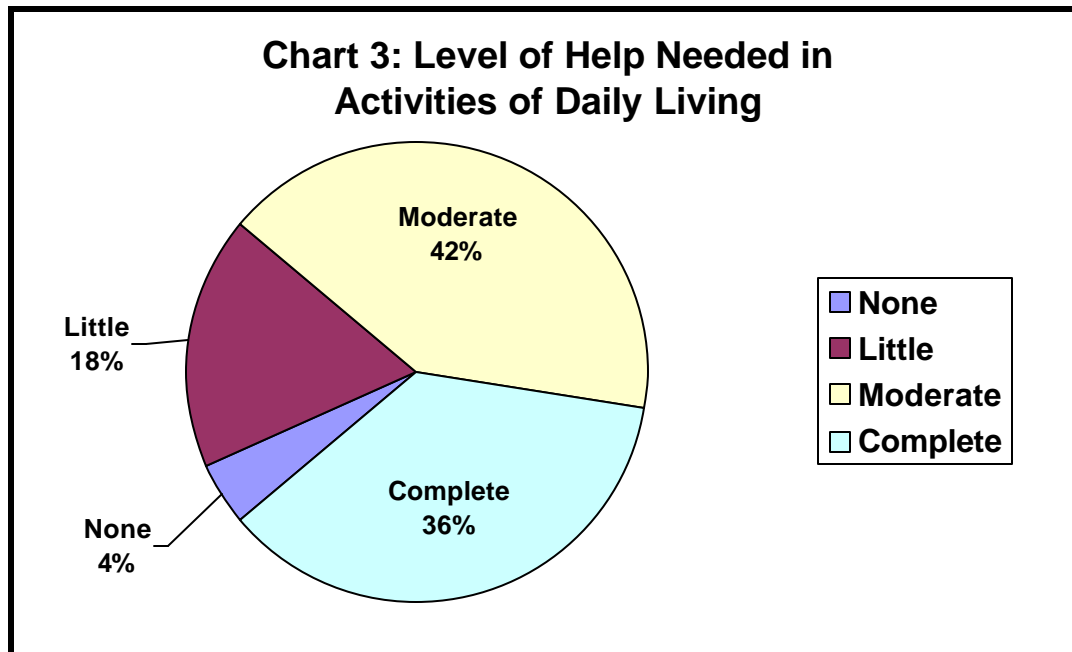


Table 9 Level of Help with Daily Activities				
State	None	Little	Moderate	Complete
AZ	3.6	13.4	44.8	38.3
CA-RCOC	5.9	19.9	32.9	41.4
MA	6.0	21.1	43.1	29.8
SC	8.1	21.2	43.4	27.3
SD	1.8	14.2	42.0	42.0
WA	1.7	14.9	48.2	35.2
WY	3.8	19.4	36.0	40.9
Total n	112	449	1,005	942
Total %	4.5	17.9	40.1	37.6
State Avg. %	4.4	17.7	41.5	36.4

Family Member's Disabilities

- Many families indicated that their children have mental retardation (43%) and/or other developmental disabilities (32%). Additionally, many children experience other disabilities, such as autism (26%), physical disabilities (26%), seizure disorders (25%), communication disorders (24%), vision or hearing impairments, and/or cerebral palsy (21%).

Table 10A Disabilities of Child						
State	Mental Retardation	Other Dev. Disability	Mental Illness	Autism	Cerebral Palsy	Brain Injury
AZ	36.8	33.0	3.8	20.3	26.1	7.0
CA-RCOC	37.3	13.4	1.8	37.3	16.0	5.2
MA	40.2	32.2	6.3	37.1	16.9	5.4
SC	36.3	40.7	3.3	21.1	14.4	3.3
SD	45.3	34.1	2.4	15.9	27.6	11.2
WA	36.8	37.0	4.9	27.6	21.0	7.5
WY	66.8	29.9	3.2	21.4	22.5	12.8
Total n	1013	675	88	752	494	171
Total %	40.3	26.8	3.5	29.9	19.6	6.8
State Avg. %	42.8	31.5	3.7	25.8	20.6	7.5

Table 10B Disabilities of Child							
State	Seizure Disorder/ Neurological Problem	Chemical Dependency	Vision or Hearing Impairments	Physical Disability	Communication Disorder	Down Syndrome	Other Disability
AZ	24.4	0.3	29.0	23.2	20.0	14.2	24.1
CA-RCOC	16.9	0.5	13.3	14.9	22.0	16.7	11.7
MA	21.3	0.5	22.1	22.9	24.8	12.5	25.6
SC	23.3	1.1	16.7	26.7	19.8	10.1	28.9
SD	30	0.0	22.4	37.6	25.3	*	17.6
WA	31.7	0.4	25.7	26.3	25.9	12.0	27.4
WY	28.9	0.5	23.5	26.7	27.3	16.6	26.7
Total n	586	11	516	557	588	339	515
Total %	23.3	0.4	20.5	22.2	23.4	14.5	20.5
State Avg. %	25.2	0.5	21.8	25.5	23.6	13.7	23.1

* Question not asked in South Dakota

Characteristics of Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the individual with disabilities living in the household.

Age of Respondent

- ♦ Across all states, nearly three-quarters (71%) of respondents fell into the age category of 35 to 54 years old. Twenty-one percent of respondents were under 35, and the remaining 7% were over 55.

Table 11 Age of Respondent (%)				
State	Under 35	35-54	55-74	75 or Older
AZ	39.5	55.0	5.2	0.3
CA-RCOC	18.0	71.9	9.2	0.9
MA	11.9	82.1	5.4	0.5
SC	24.3	63.1	10.7	0.1
SD	17.2	81.1	1.8	0.0
WA	21.3	71.5	7.0	0.2
WY	18.2	72.7	8.2	0.0
Total n	534	1,825	186	14
Total %	20.9	71.3	7.3	0.5
State Avg. %	21.5	71.1	6.8	0.3

Relationship of Respondent to Individual with Disabilities

- ♦ The vast majority of respondents were parents of children with disabilities (95%). The remaining respondents were grandparents (4%), or others(1%).

Table 12 Relationship to Child with Disabilities (%)				
State	Parent	Sibling	Grand-parent	Other
AZ	96.0	0.3	3.5	0.3
CA-RCOC	97.8	0.0	1.6	0.5
MA	97.0	0.5	1.6	0.8
SC	91.2	0.0	5.9	2.9
SD	97.6	0.0	1.8	0.6
WA	94.9	0.0	4.4	0.6
WY	93.0	0.0	5.9	1.1
Total n	2,463	3	74	18
Total %	96.3	0.1	2.9	0.7
State Avg. %	95.4	0.1	3.5	1.0

Respondent's Role as Primary Caregiver

- ♦ In total, 98% of all respondents were the primary caregiver for their child with disabilities. This was consistent across all of the states.

Table 13 Respondent is Primary Caregiver		
State	% Yes	% No
AZ	99.1	0.9
CA-RCOC	97.6	2.4
MA	98.3	1.7
SC	99.0	1.0
SD	98.8	1.2
WA	96.6	3.4
WY	97.8	2.2
Total n	2,489	54
Total %	97.9	2.1
State Avg. %	98.2	1.8

Health of Respondent

- ♦ Most respondents (individuals who completed the surveys) indicated that they were in good (52%) or excellent (30%) health. Eighteen percent, however, categorized their health as being fair or poor.

Table 14 Health of Respondent (%)				
State	Excellent	Good	Fair	Poor
AZ	34.8	47.5	13.9	3.8
CA-RCOC	30.6	48.3	19.1	2.0
MA	35.3	46.7	15.8	2.2
SC	25.2	52.4	18.4	3.9
SD	29.0	57.4	12.4	1.2
WA	24.7	54.3	18.7	2.3
WY	30.5	54.5	13.4	1.6
Total n	775	1,282	432	59
Total %	30.4	50.3	17.0	2.3
State Avg. %	30.0	51.6	16.0	2.4

Household Income

- ◆ Nearly half (43%) of respondents had an annual household income (including all wage earners within the household) of \$25,000 or less. 28% had a household income between \$25,001 and \$50,00, and 29% had an income over \$50,000.

Table 15 Household Income					
State	Below \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000
AZ	26.6	21.9	23.8	13.4	13.4
CA-RCOC	22.7	22.2	21.3	14.1	19.7
MA	17.8	9.9	26.6	17.8	28.0
SC	41.1	24.2	18.9	6.3	9.5
SD	15.5	23.6	41.0	12.4	7.5
WA	24.2	15.3	30.2	19.9	10.4
WY	20.0	16.0	35.4	23.4	5.1
Total n	549	453	633	382	390
Total %	22.8	18.8	26.3	15.9	16.2
State Avg. %	24.0	19.0	28.2	15.3	13.4

Services and Supports Received

- ♦ Across participating states, on average, specialized services and supports were most often utilized (71%) by families having a child with disabilities.
- ♦ Additionally, 41% used out-of-home respite, 37% received SSI financial support, 37% obtained in-home supports, and 36% received other types of financial support.

Table 16 Services and Supports Received (%)							
State	SSI financial support	Other financial support	In-home support	Out-of-home respite care	Early intervention	Transportation	Specialized services/ supports
AZ	41.1	13.4	45.4	29.9	25.1	15.4	84.2
CA-RCOC	34.8	11.0	26.1	36.3	20.0	11.8	59.3
MA	28.9	60.2	36.5	18.5	11.3	6.8	68.7
SC	52.9	20.2	26.0	22.8	40.4	16.0	62.8
SD	39.1	64.0	25.9	53.0	26.1	10.4	85.9
WA	22.9	38.6	42.8	56.8	4.3	7.3	57.5
WY	40.2	42.9	54.7	75.3	10.1	11.8	81.6
Total n	827	670	827	921	402	266	1,560
Total Avg. %	34.5	29.4	35.1	39.3	17.4	10.9	68.1
State Avg. %	37.1	35.8	36.8	41.8	19.6	11.4	71.4

National Core Indicators

In these next several sections, the questions and results are discussed that tie directly to the National Core Indicator domains for assessing service and support quality. These questions are grouped as they pertain to 1) information and planning; 2) access and delivery of services and supports; 3) choice and control; 4) community connections; and 5) overall satisfaction and outcomes.

For each question, a Figure and Table is provided.

- ♦ The Figure illustrates the State Average results (i.e., the average percentage across the thirteen states and one local DD authority that conducted this survey).
- ♦ The Table details individual state results, total percentage (i.e., the percentage of all respondents) and state average (i.e., the average percentage of the state-by-state results).
- ♦ In the Tables, a (↑) next to a state name indicates, that its results are **5% or more ABOVE** the state average among respondents who answered “Yes or Most of the Time” to each question.
- ♦ In the Tables, a (↑ ↑) next to a state name indicates, that its results are **10% or more ABOVE** the state average among respondents who answered “Yes or Most of the Time” to each question.
- ♦ A (↓) next to a state name indicates that its results are **5% or more BELOW** the state average among respondents who answered “Yes or Most of the Time” to each question.
- ♦ A (↓ ↓) next to a state name indicates that its results are **10% or more BELOW** the state average among respondents who answered “Yes or Most of the Time” to each question.
- ♦ In general, when a Table has many arrows (up and down), it indicates that there is considerable variance in results among states. When there are few arrows, responses across states are more uniform.

Following all of the individual question results, an overview of results by topic grouping (e.g., information and planning, choice and control) is offered, providing a crude overview of how states measured up, overall, against the state averages.

Information and Planning

- ♦ Across states, fewer than half (45%) of respondents indicated they regularly receive information about the services and supports available to them. Individual state results varied considerably, ranging from 30% in Washington and Massachusetts to 63% in Orange County, CA.

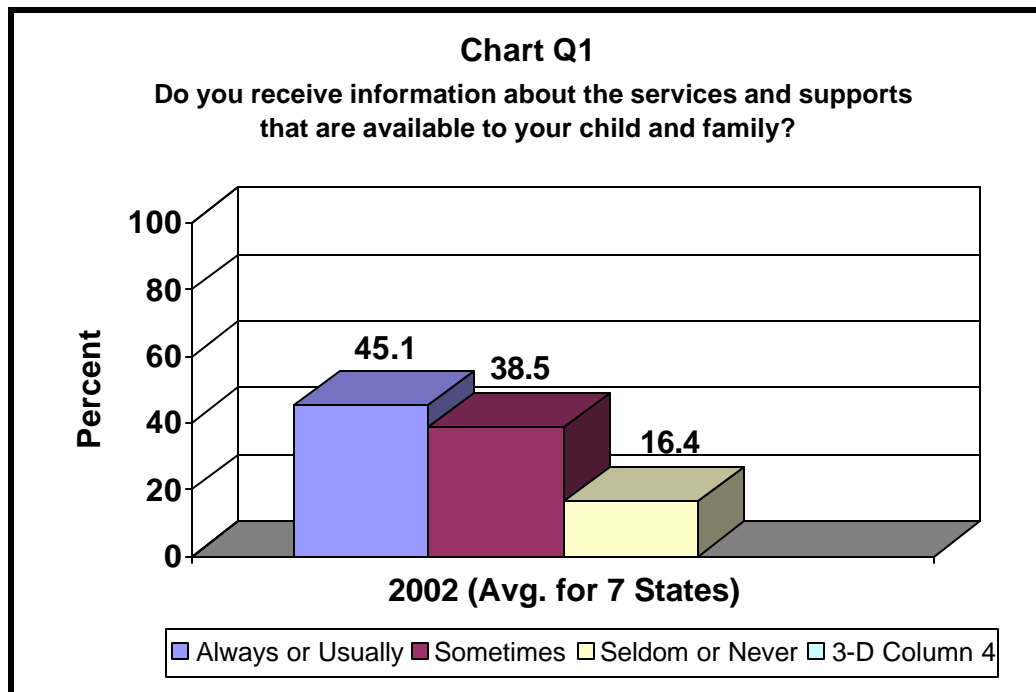


Table Q1					
Do you receive information about the services and supports that are available to your child and family?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		44.8	37.9	17.3	330
CA-RCOC	↑↑	63.4	29.4	7.2	887
MA	↓↓	31.2	45.1	23.7	359
SC		49.0	32.7	18.4	98
SD	↑↑	55.6	36.7	7.7	169
WA	↓↓	29.9	41.5	28.6	465
WY		41.8	46.2	12.1	182
Total %		47.3	36.9	15.7	Total n = 1179
State Average		45.1	38.5	16.4	Total n = 7

- ♦ Among those who receive information, over half (60%) found the information easy to understand, while the remaining 40% found the information, at least sometimes, difficult to understand.

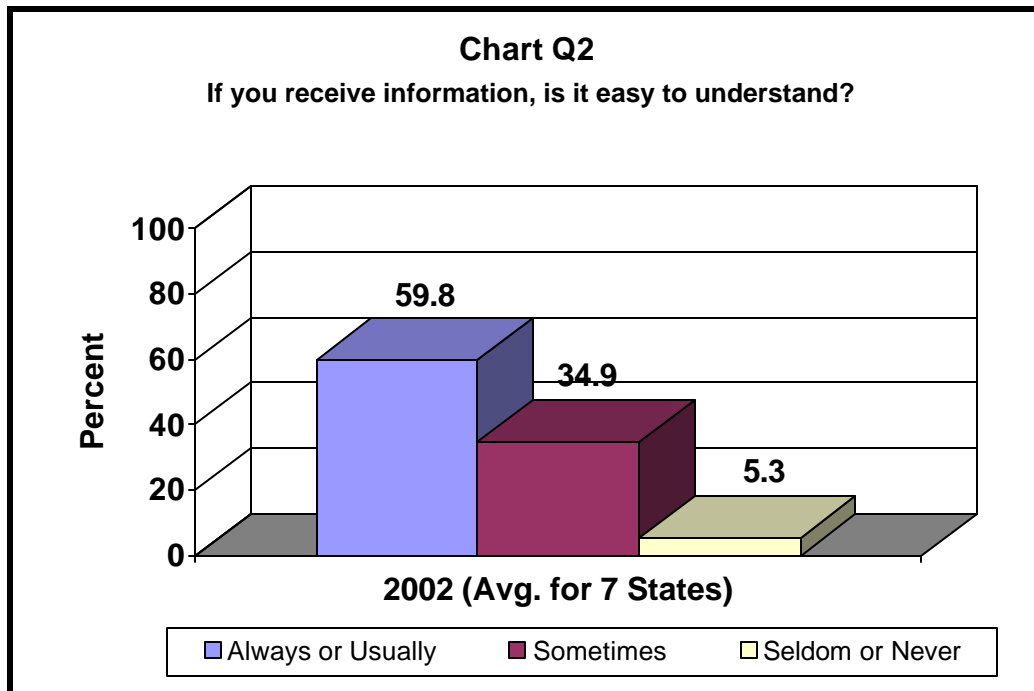


Table Q2					
If you receive information, is it easy to understand?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		61.2	33.3	5.5	309
CA-RCOC	↑	66.2	29.3	4.6	851
MA		60.8	34.1	5.1	314
SC		60.0	34.4	5.6	90
SD	↑↑	72.0	25.6	2.4	168
WA	↓↓	48.5	42.3	9.2	402
WY	↓	50.0	45.3	4.7	172
Total %		60.7	33.9	5.5	Total n = 2306
State Average		59.8	34.9	5.3	Total n = 7

- ♦ Across states, half (49%) of respondents indicated they regularly receive information about their child's disability or development. Once again, individual state results varied quite a bit, ranging from 33% in Washington to 60% in Arizona.

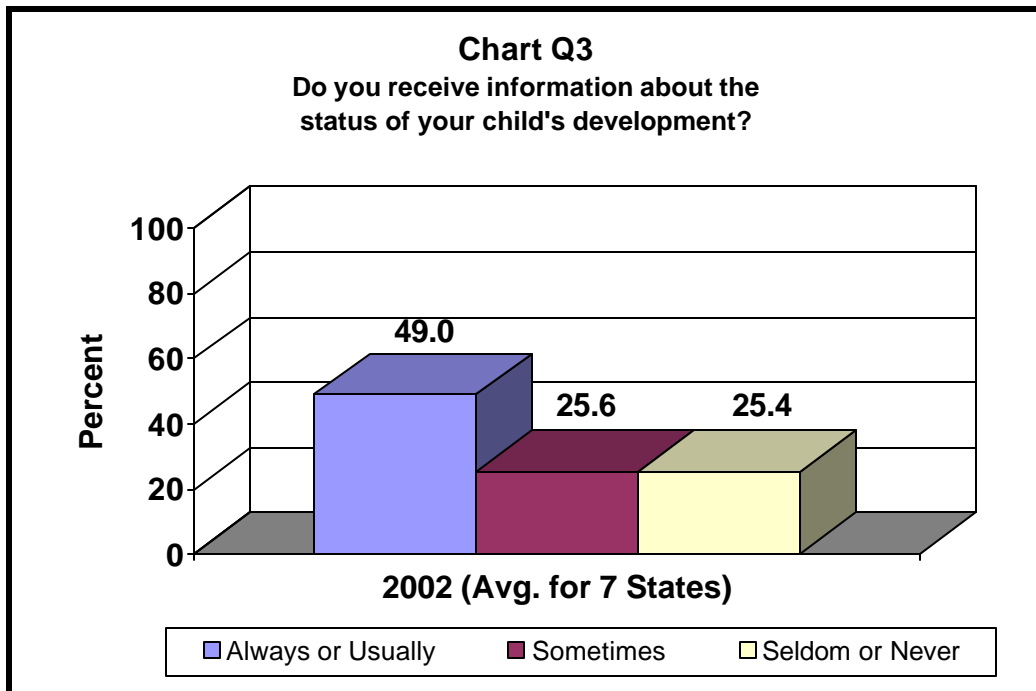


Table Q3 Do you receive information about the status of your child's development?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑↑	60.3	21.5	18.2	335
CA-RCOC	↓	42.1	29.6	28.3	805
MA		47.9	19.6	32.5	311
SC	↑	55.9	24.7	19.4	93
SD		51.6	30.7	17.6	153
WA	↓↓	33.3	21.7	45.1	415
WY		52.2	31.1	16.7	180
Total %		45.9	25.6	28.4	Total n = 2292
State Average		49.0	25.6	25.4	Total n = 7

- ♦ Among those who receive this information, 62% found it easy to understand, and the remaining 38% found the information, at least sometimes, difficult to understand.

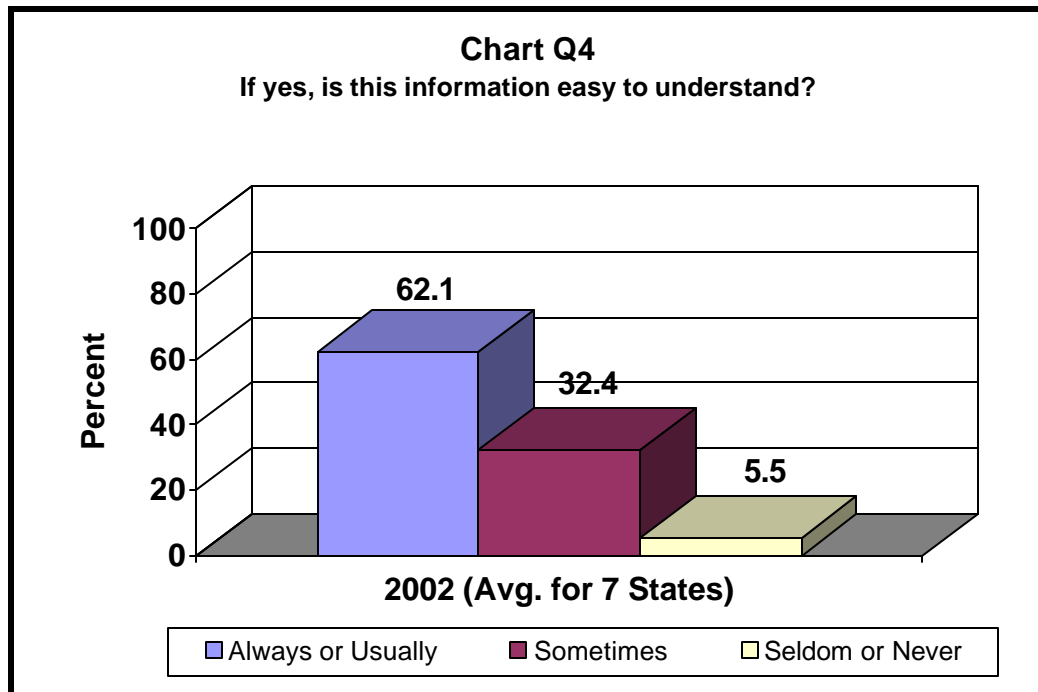


Table Q4 If yes, is this information easy to understand?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑↑	72.6	22.9	4.5	292
CA-RCOC		62.1	31.0	6.9	642
MA		65.5	30.7	3.8	238
SC		62.8	30.2	7.0	86
SD		62.2	34.1	3.7	135
WA	↓↓	52.1	38.2	9.7	288
WY		57.3	39.5	3.2	157
Total %		62.3	31.7	6.0	Total n = 1838
State Average		62.1	32.4	5.5	Total n = 7

- ♦ Half of respondents (48%) stated they got enough information to help them participate in planning, however the other half (52%) indicated they only sometimes or seldom had enough information.

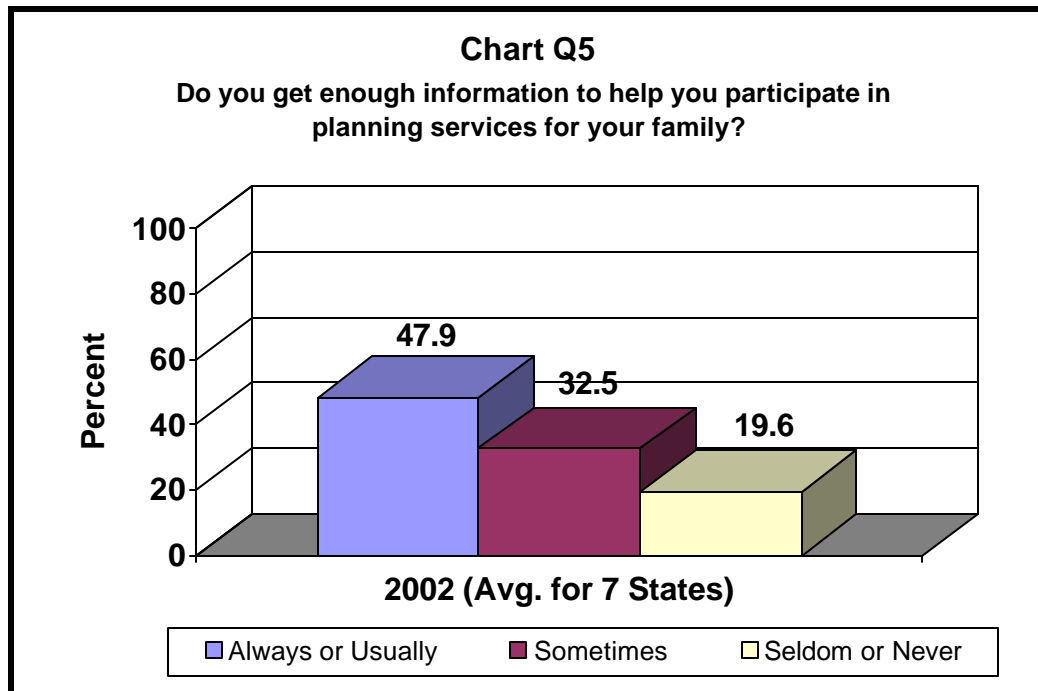


Table Q5 Do you get enough information to help you participate in planning services for your family?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		49.2	31.4	19.4	325
CA-RCOC		44.4	34.5	21.0	822
MA	↓↓	31.5	37.0	31.5	324
SC	↑↑	60.0	26.3	13.7	95
SD	↑↑	61.1	30.6	8.3	157
WA	↓↓	32.4	35.2	32.4	426
WY	↑	56.7	32.6	10.7	178
Total %		43.8	33.8	22.4	Total n = 2327
State Average		47.9	32.5	19.6	Total n = 7

- ◆ Nearly three-quarters (70%) of respondents, on average across states, indicated that they typically help in developing their family member's service plan.

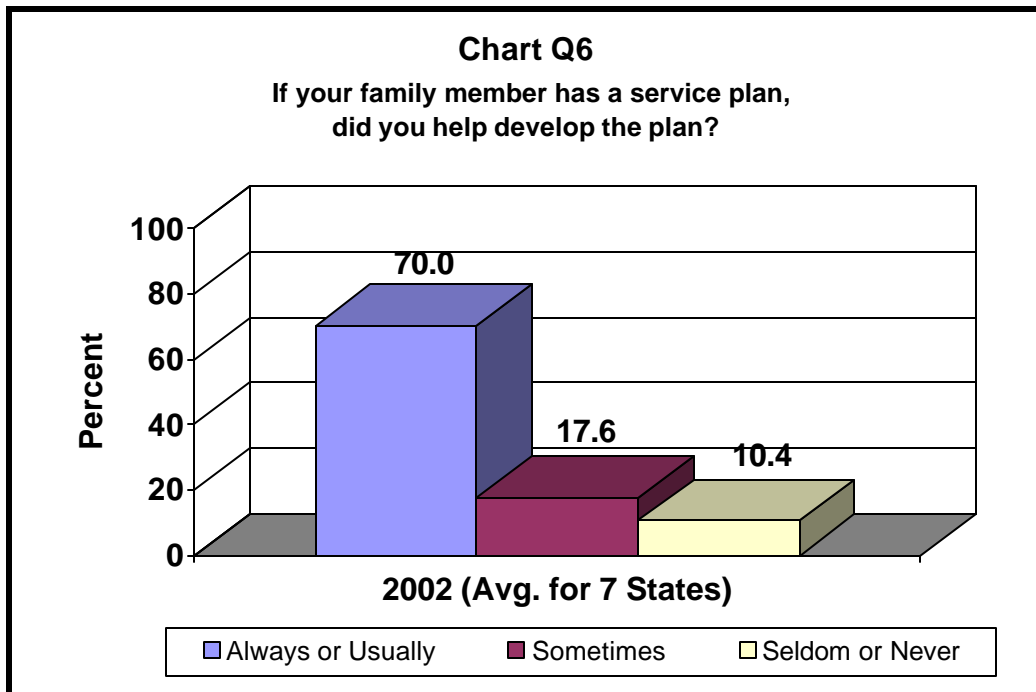


Table Q6					
If your family member has a service plan, did you help develop the plan?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		74.6	17.3	8.1	260
CA-RCOC	↓	66.6	20.0	13.4	640
MA	↓↓	61.4	18.6	20.0	210
SC		67.8	23.0	9.2	87
SD	↑	79.3	17.2	3.4	145
WA	↓	64.6	18.2	17.2	291
WY	↑↑	89.6	9.2	1.2	163
Total %		70.0	18.1	11.9	Total n = 1796
State Average		72.0	17.6	10.4	Total n = 7

- ♦ Of those families with a service plan, 72% stated that the plan included things important to the respondent. Over one quarter of respondents (28%) indicated that the plan only sometimes, seldom or never included things important to them. South Dakota had notably higher results, with 82% of respondents stating the plan reflected goals important to them

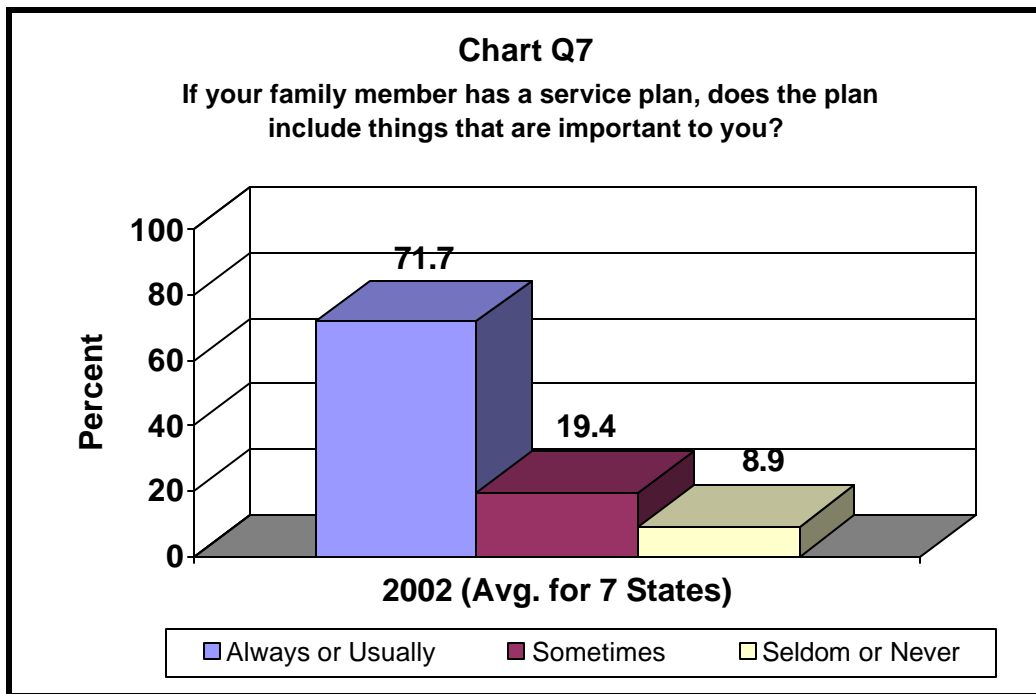


Table Q7 If your family member has a service plan, does the plan include things that are important to you?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		73.4	20.2	6.5	263
CA-RCOC	↓↓	61.0	25.8	13.1	616
MA		67.2	17.6	15.2	204
SC		73.0	15.7	11.2	89
SD	↑↑	81.8	14.7	3.5	143
WA	↓↓	60.4	28.3	11.3	293
WY	↑↑	85.2	13.6	1.2	162
Total %		68.0	21.9	10.1	Total n = 1770
State Average		71.7	19.4	8.9	Total n = 7

- ♦ Across states, over half (57%) indicated that planning staff would help them figure out the supports they needed. However, a large percentage (43%) stated that this was only sometimes or even seldom the case.

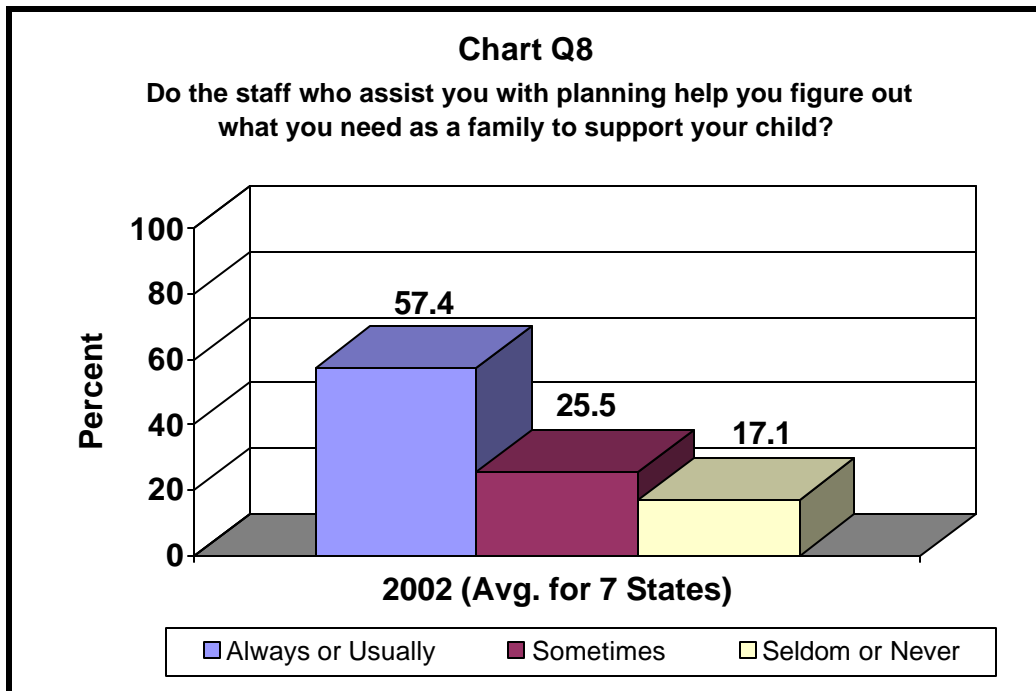


Table Q8 Do the staff who assist you with planning help you figure out what you need as a family to support your child?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		60.3	24.0	15.8	292
CA-RCOC	↓↓	41.3	34.6	24.1	818
MA	↓↓	45.1	28.5	26.4	235
SC	↑↑	68.5	18.5	13.0	92
SD	↑↑	75.3	18.0	6.7	150
WA	↓↓	43.8	31.0	25.3	352
WY	↑↑	67.8	23.6	8.6	174
Total %		50.5	29.1	20.4	Total n = 2113
State Average		57.4	25.5	17.1	Total n = 7

- ♦ Across states, approximately three-quarters (77%) of respondents felt that staff respect their choices and opinions.

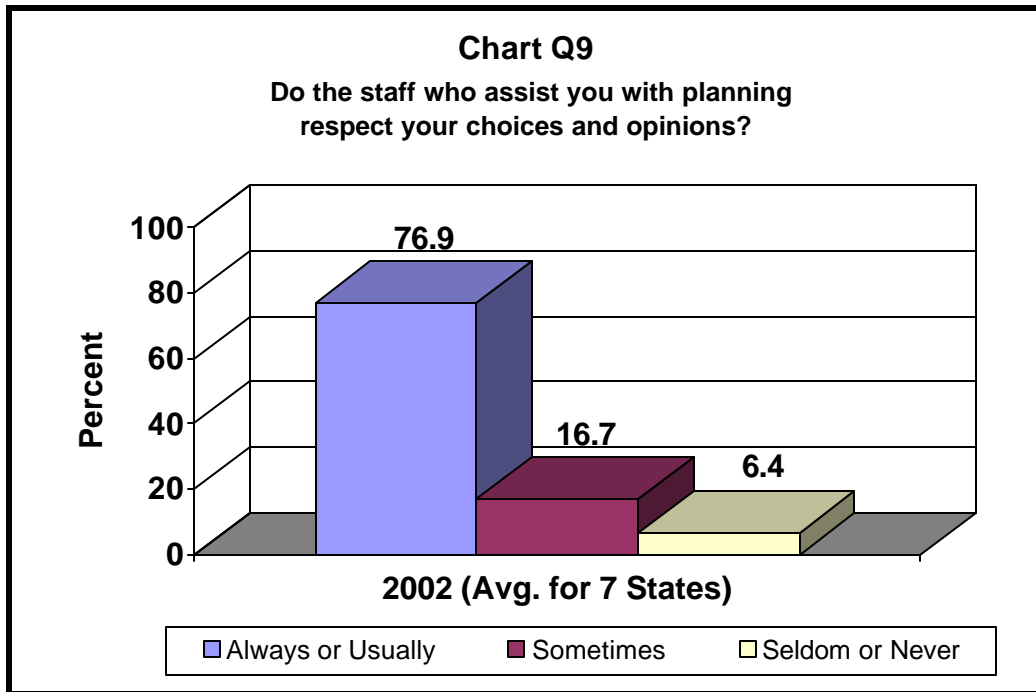


Table Q9					
Do the staff who assist you with planning respect your choices and opinions?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		80.5	14.6	4.9	287
CA-RCOC		73.5	19.2	7.3	791
MA	↓	71.1	17.1	11.8	228
SC		78.0	17.6	4.4	91
SD	↑	83.1	13.6	3.2	154
WA	↓	70.6	19.8	9.6	344
WY		81.5	15.0	3.5	173
Total %		75.3	17.6	7.1	Total n = 2068
State Average		76.9	16.7	6.4	Total n = 7

- ♦ Only one-third (36%) of respondents indicated that planning staff discussed with them the public benefits that may or may not be available to them. Another quarter occasionally received this information, while 39% indicated that planning staff did not relay this information to them. Results were fairly consistent across states, with the exception of South Carolina (in which approximately half of families did discuss public benefits) and Massachusetts (where fewer than one-fourth of families had these discussions).

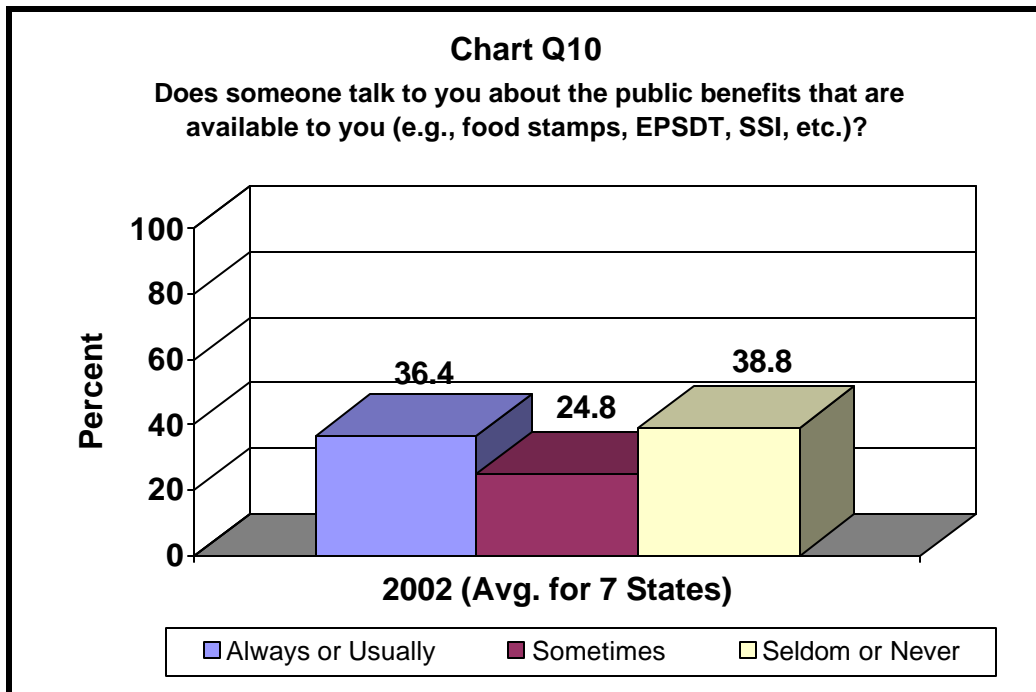


Table Q10					
Does someone talk to you about the public benefits that are available to you (e.g., food stamps, EPSDT, SSI, etc.)?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		37.0	20.8	42.2	289
CA-RCOC		34.7	26.9	38.4	796
MA	↓↓	22.3	22.6	55.1	283
SC	↑↑	52.1	22.3	25.5	94
SD	↑	46.3	32.9	20.8	149
WA	↓	27.0	22.9	50.1	397
WY		35.2	25.5	39.4	165
Total %		33.5	24.9	41.6	Total n = 2173
State Average		36.4	24.8	38.8	Total n = 7

- ♦ Among all respondents, 897% felt that agency staff were generally respectful and courteous. Across all states, these results were fairly consistent.

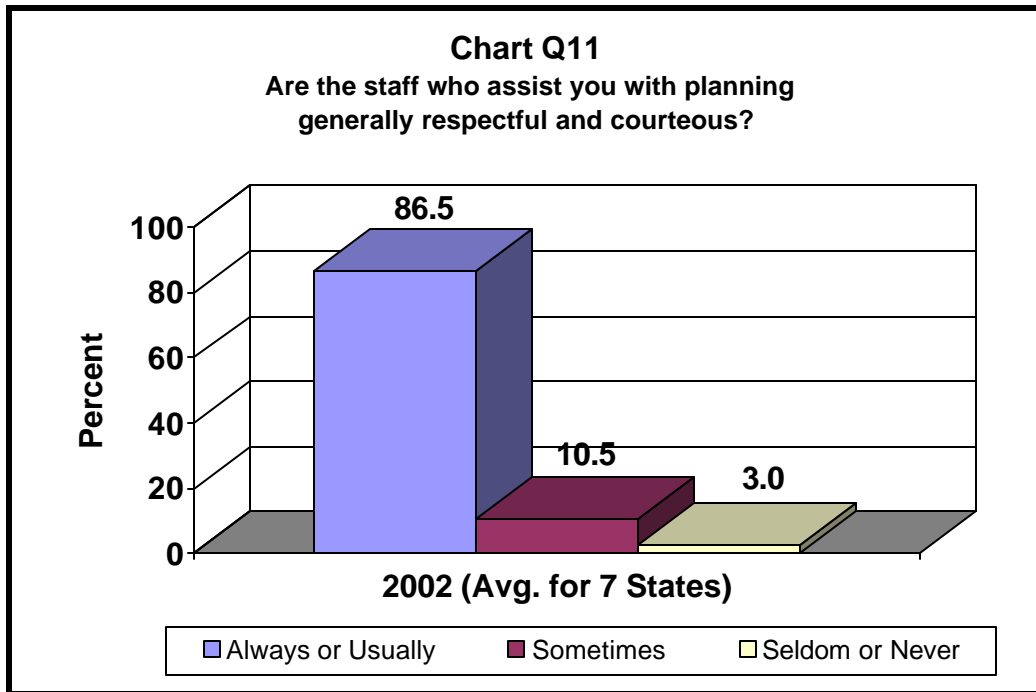


Table Q11 Are the staff who assist you with planning generally respectful and courteous?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		86.6	10.8	2.5	314
CA-RCOC		84.3	12.9	2.7	875
MA		83.5	10.2	6.3	255
SC		86.0	9.7	4.3	93
SD	↑	92.6	6.2	1.2	162
WA		83.0	15.0	2.0	400
WY		89.3	9.0	1.7	178
Total %		85.4	11.8	2.9	Total n = 2277
State Average		86.5	10.5	3.0	Total n = 7

- ◆ Among all respondents, 67% felt that agency staff were generally effective.

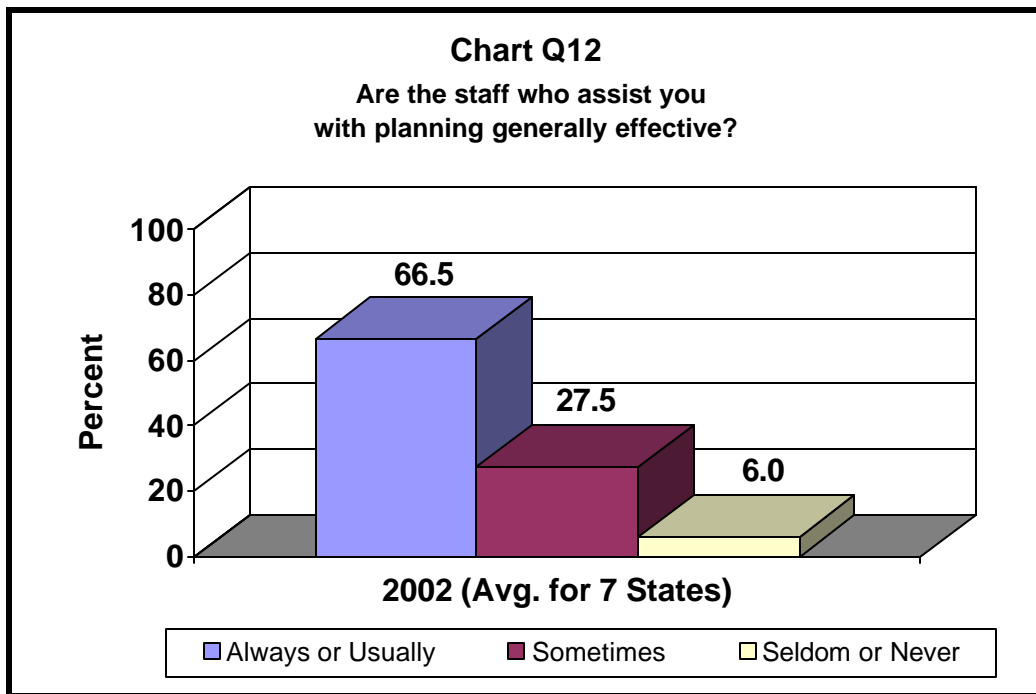


Table Q12 Are the staff who assist you with planning generally effective?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		66.0	27.8	6.2	306
CA-RCOC	↓	59.2	33.1	7.6	839
MA	↓↓	54.5	35.6	9.9	253
SC	↑	72.5	22.0	5.5	91
SD	↑↑	84.0	14.8	1.2	162
WA	↓	57.4	34.5	8.2	380
WY	↑	71.9	24.7	3.4	178
Total %		62.7	30.4	6.9	Total n = 2209
State Average		66.5	27.5	6.0	Total n = 7

- ♦ Across all states, fewer than three-quarters (71%) of respondents indicated they could typically contact staff when desired.

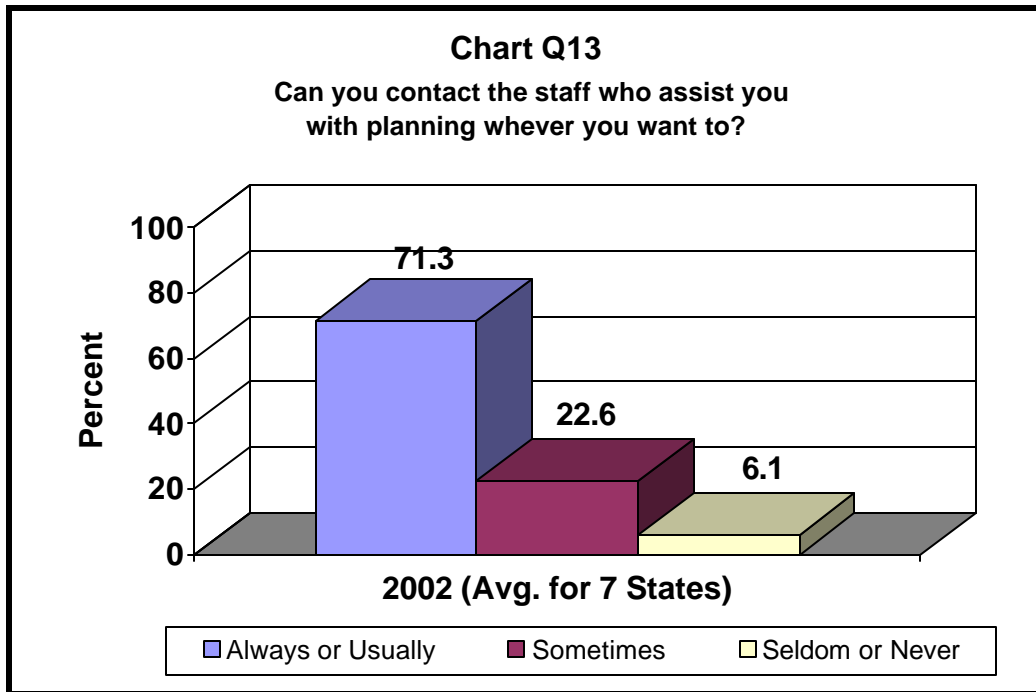


Table Q13					
Can you contact the staff who assist you with planning whenever you want to?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		69.5	23.4	7.1	308
CA-RCOC		68.8	25.9	5.3	852
MA	↓	61.6	30.2	8.2	255
SC		75.8	17.6	6.6	91
SD	↑↑	84.0	13.6	2.5	162
WA	↓↓	59.4	31.0	9.6	394
WY	↑	80.2	16.4	3.4	177
Total %		68.7	25.0	6.3	Total n = 2239
State Average		71.3	22.6	6.1	Total n = 7

Access to and Delivery of Services and Supports

- Overall, 68% of families stated their service coordinator helped them get needed supports when asked. Twenty-five percent said this happened sometimes, and 7% indicated that their service coordinator was rarely helpful in getting the assistance needed.

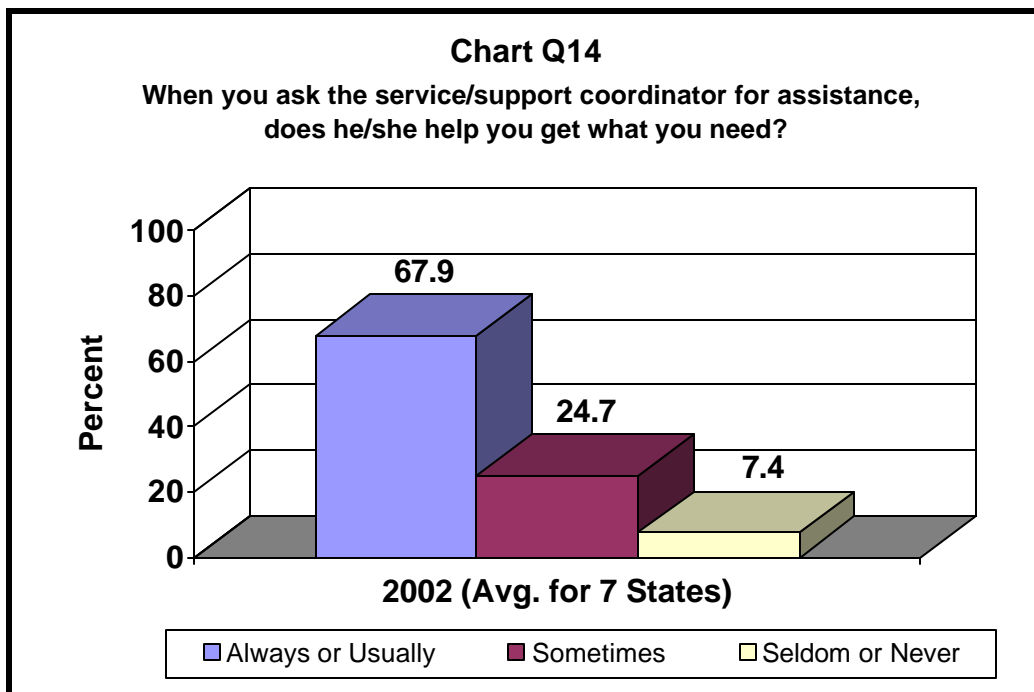


Table Q14					
When you ask the service/support coordinator for assistance, does he/she help you get what you need?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		68.0	25.1	6.9	334
CA-RCOC	↓↓	47.0	35.0	18.0	734
MA	↓↓	57.5	34.0	8.4	285
SC		70.4	19.4	10.2	98
SD	↑↑	89.0	9.8	1.2	163
WA		64.5	29.9	5.7	442
WY	↑↑	79.2	19.7	1.1	178
Total %		61.6	28.6	9.8	Total n = 2234
State Average		67.9	24.7	7.4	Total n = 7

- ♦ Fifty-four percent of respondents said they always or usually get the services and supports needed. Thirty-six percent got needed supports some of the time, and the remaining 10% seldom or never received needed supports.

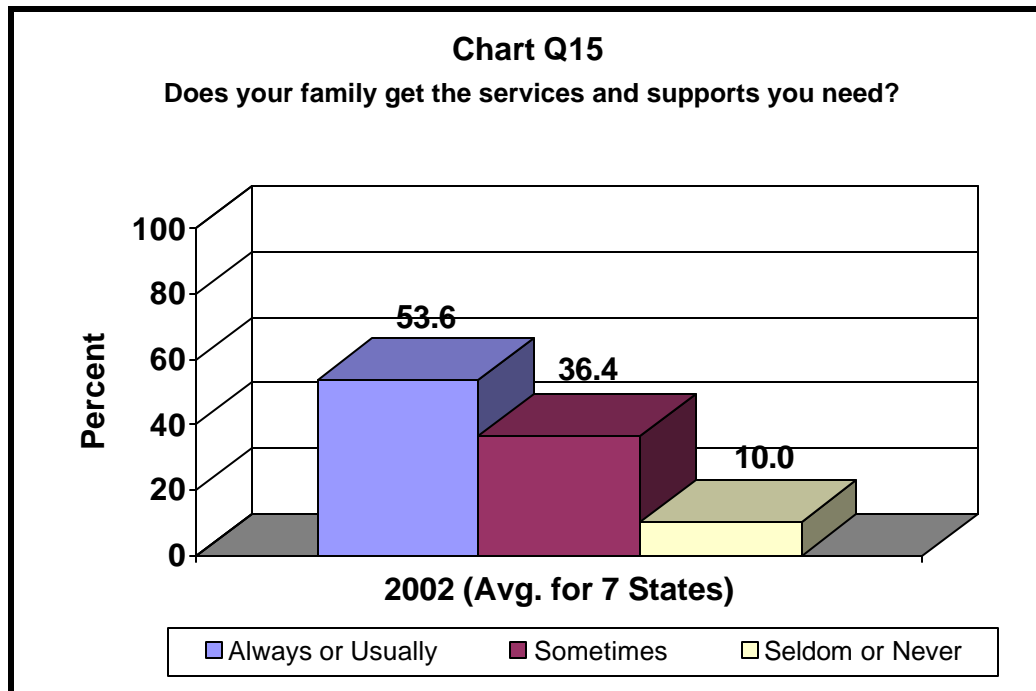


Table Q15 Does your family get the services and supports you need?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		56.3	34.4	9.3	334
CA-RCOC		49.0	40.0	11.1	823
MA	↓↓	34.4	45.4	20.2	317
SC	↑	60.8	26.8	12.4	97
SD	↑↑	75.0	23.2	1.8	164
WA	↓↓	41.9	46.0	12.1	446
WY		58.0	39.2	2.8	181
Total %		49.7	39.3	11.0	Total n = 2362
State Average		53.6	36.4	10.0	Total n = 7

- ♦ Among all respondents, about half (51%) said that the supports received met their families' needs, although this varied quite a bit from state to state. Another 38% said that the supports sometimes met their needs, while the remaining 11% seldom or never felt the supports offered met their family's needs.

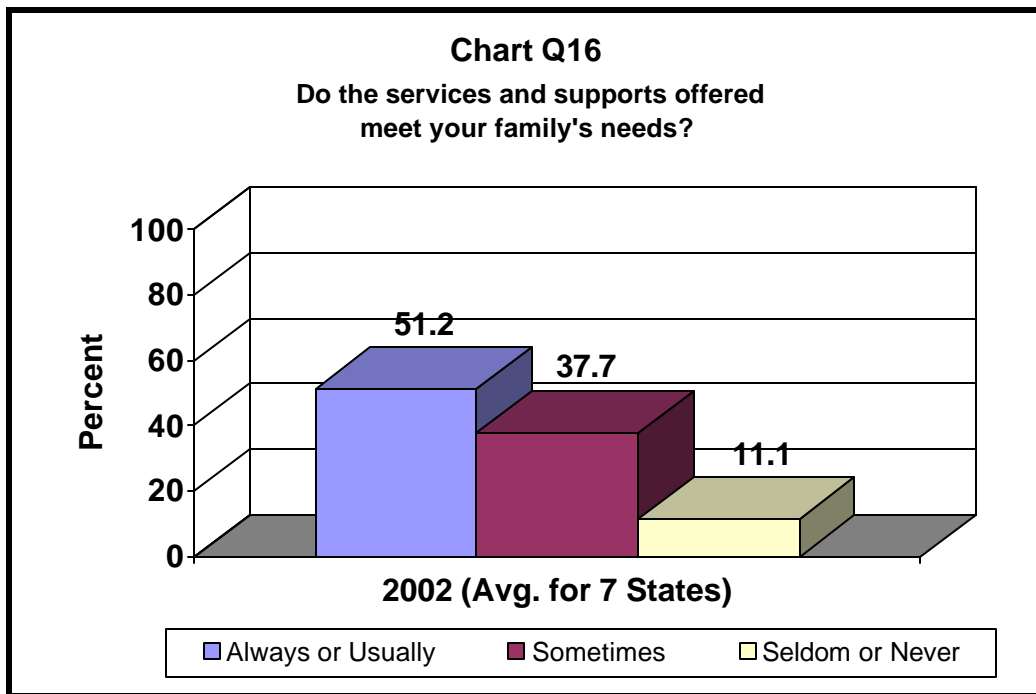


Table Q16					
Do the services and supports offered meet your family's needs?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		52.6	38.5	8.9	327
CA-RCOC	↓	44.0	41.3	14.7	797
MA	↓↓	35.2	42.2	22.5	315
SC	↑	58.2	31.6	10.2	98
SD	↑↑	70.8	26.2	3.0	168
WA	↓↓	36.7	48.8	14.5	441
WY	↑	61.1	35.0	3.9	180
Total %		46.5	40.5	13.0	Total n = 2326
State Average		51.2	37.7	11.1	Total n = 7

- ♦ For less than half of families (46%), supports were always or usually available when needed. However, almost as many families indicated that supports were only sometimes available (41%), or not available (12%) when needed.

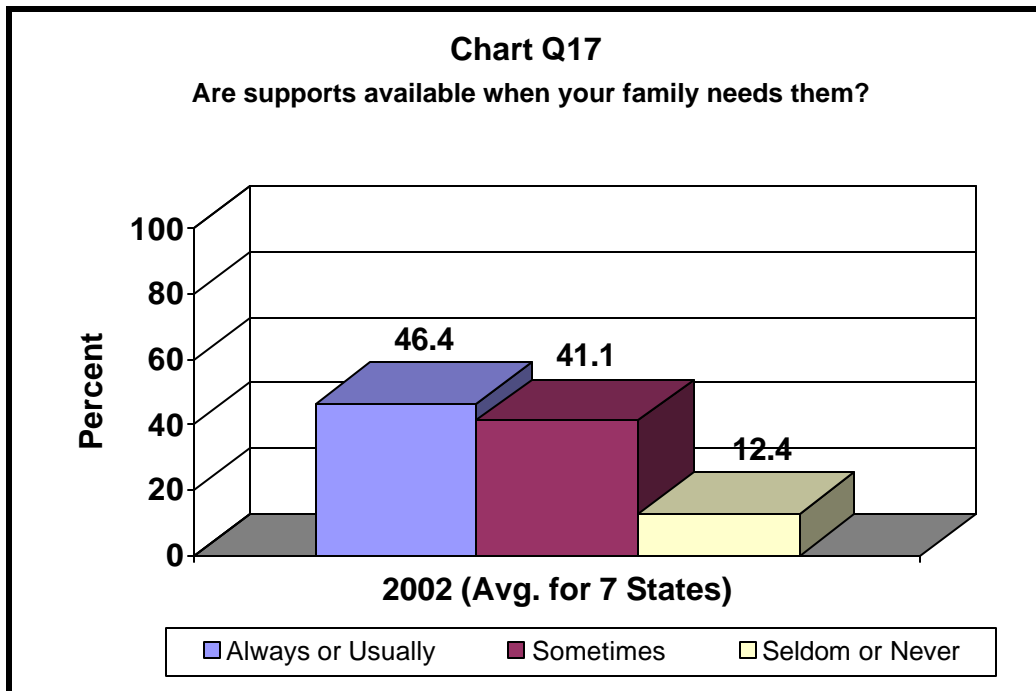


Table Q17 Are supports available when your family needs them?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		46.7	41.7	11.5	321
CA-RCOC		43.1	42.5	14.4	764
MA	↓↓	31.2	46.7	22.1	317
SC	↑	54.8	33.3	11.8	93
SD	↑↑	66.5	29.9	3.7	164
WA	↓↓	35.6	47.6	16.8	435
WY		47.2	46.1	6.7	178
Total %		43.0	43.0	14.0	Total n = 2272
State Average		46.4	41.1	12.4	Total n = 7

- Eighty-five percent of respondents stated that families in their area at least occasionally asked for different types of supports than the ones that were currently being offered.

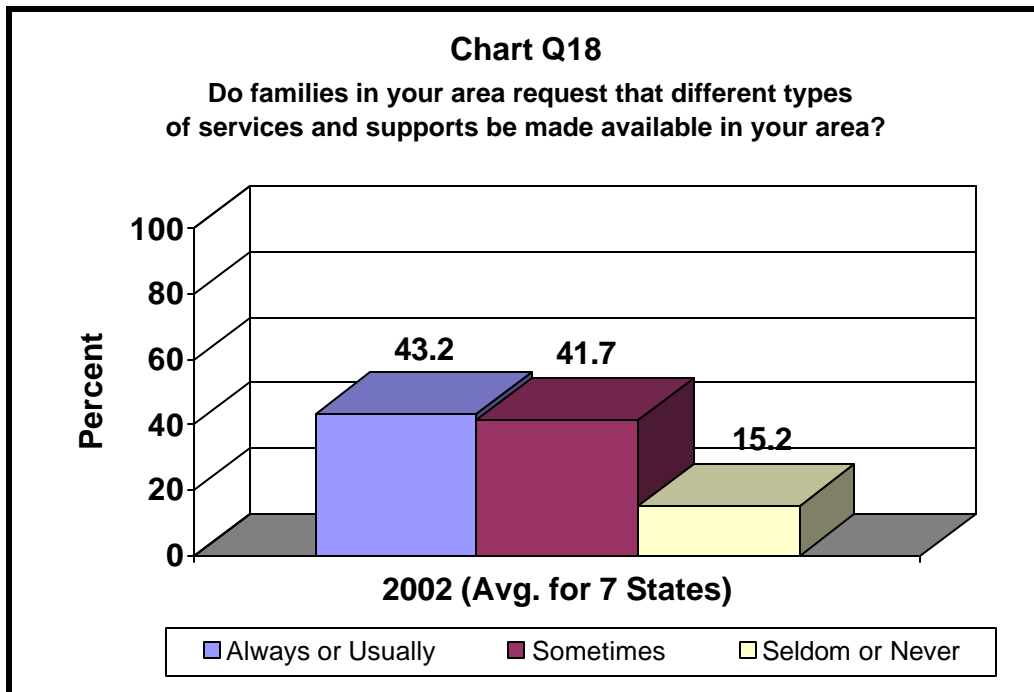


Table Q18					
Do families in your area request that different types of services and supports be made available in your area?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	50.8	34.6	14.6	130
CA-RCOC	↑	48.7	37.0	14.3	446
MA	↓↓	30.8	53.1	16.1	143
SC	↑	49.0	28.6	22.4	49
SD		43.5	43.5	13.0	46
WA		39.1	43.8	17.2	169
WY		40.4	51.1	8.5	94
Total %		44.1	41.0	14.9	Total n = 1077
State Average		43.2	41.7	15.2	Total n = 7

- ♦ On the occasions when families did request different types of supports, 38% indicated that the state agency or provider agency was usually or always responsive to these requests.

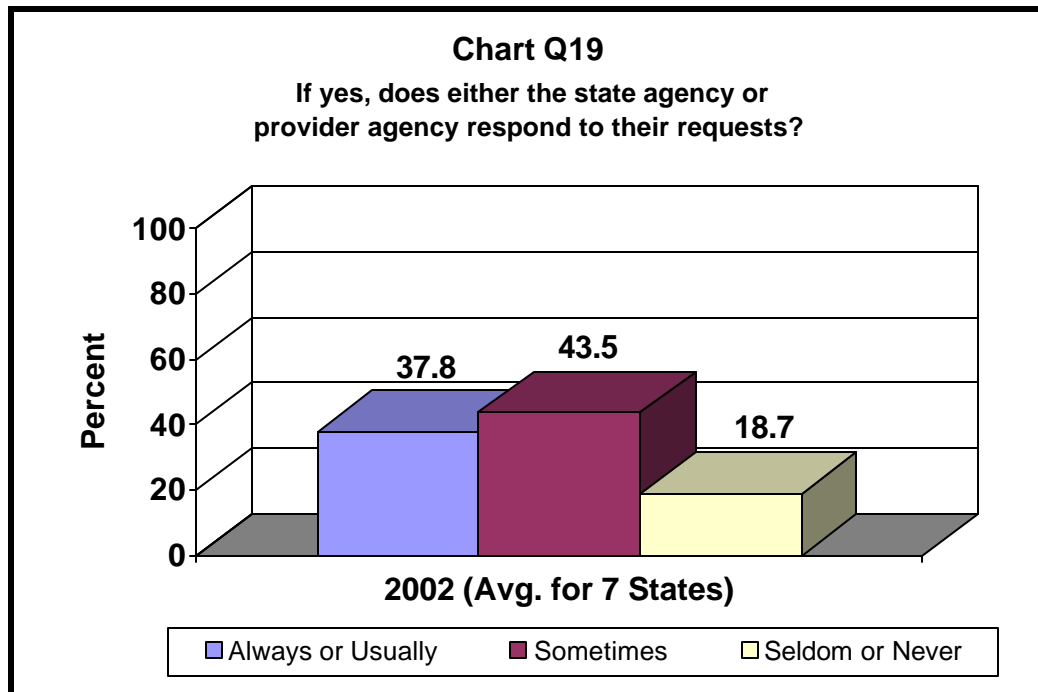


Table Q19					
If yes, does either the state agency or provider agency respond to their requests?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		37.1	48.3	14.7	116
CA-RCOC	↓	30.6	39.1	30.3	271
MA		39.0	48.8	12.2	123
SC	↑	47.4	34.2	18.4	38
SD	↑↑	61.1	30.6	8.3	36
WA	↓↓	20.3	42.2	37.5	128
WY	↓	29.2	61.1	9.7	72
Total %		33.3	43.9	22.8	Total n = 784
State Average		37.8	43.5	18.7	Total n = 7

- ♦ Slightly less than half (48%) of families who asked for assistance in an emergency or crisis did not consistently receive help right away.

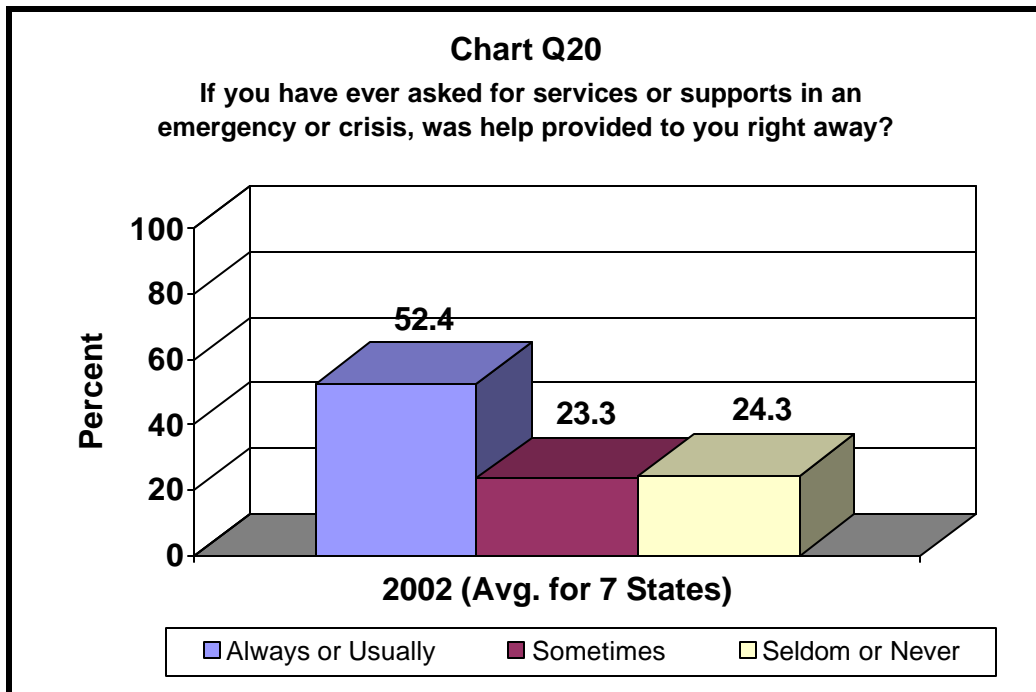


Table Q20					
If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	41.1	20.3	38.6	158
CA-RCOC		51.7	24.7	23.6	360
MA		53.1	19.4	27.5	160
SC	↑	57.9	24.6	17.5	57
SD	↑↑	74.7	16.5	8.8	91
WA	↓↓↓	35.4	26.9	37.7	212
WY		53.2	30.4	16.5	79
Total %		49.6	23.5	26.9	Total n = 1117
State Average		52.4	23.3	24.3	Total n = 7

- ♦ Among respondents whose first language was not English, a slight majority (58%) indicated that staff or translators were available to speak with them in their preferred languages. Twenty-four percent indicated that staff/translators were sometimes available, and the remaining 17% stated that staff/translators who spoke in the families' preferred languages were not available.

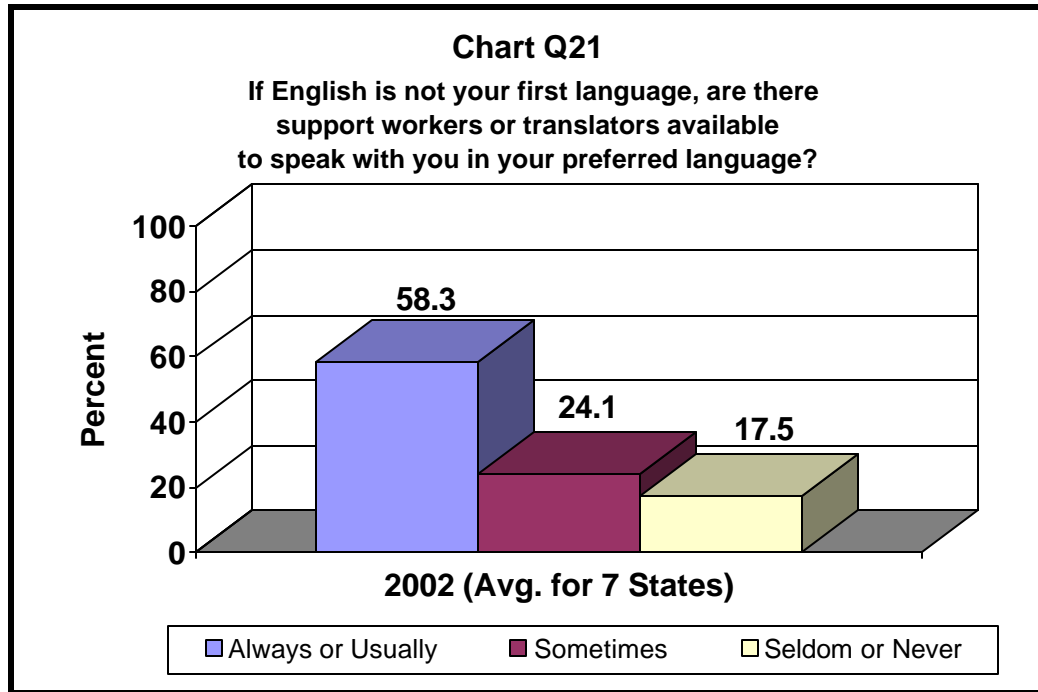


Table Q21 If English is not your first language, are there support workers or translators available to speak with you in your preferred language?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		61.5	21.5	16.9	65
CA-RCOC		53.6	22.4	24.0	250
MA		61.9	23.8	14.3	21
SC	↑↑	72.2	11.1	16.7	18
SD	↓	50.0	25.0	25.0	4
WA		59.1	25.0	15.9	44
WY	↓	50.0	40.0	10.0	10
Total %		56.6	22.6	20.9	Total n = 412
State Average		58.3	24.1	17.5	Total n = 7

- ♦ Among respondents who had children who did not speak English, or who used a different means to communicate (e.g., sign language, communication board), 40% of families said there were enough support staff regularly available who could communicate with their family member. The remaining 60%, however, said capable staff were only sometimes, seldom or never available.

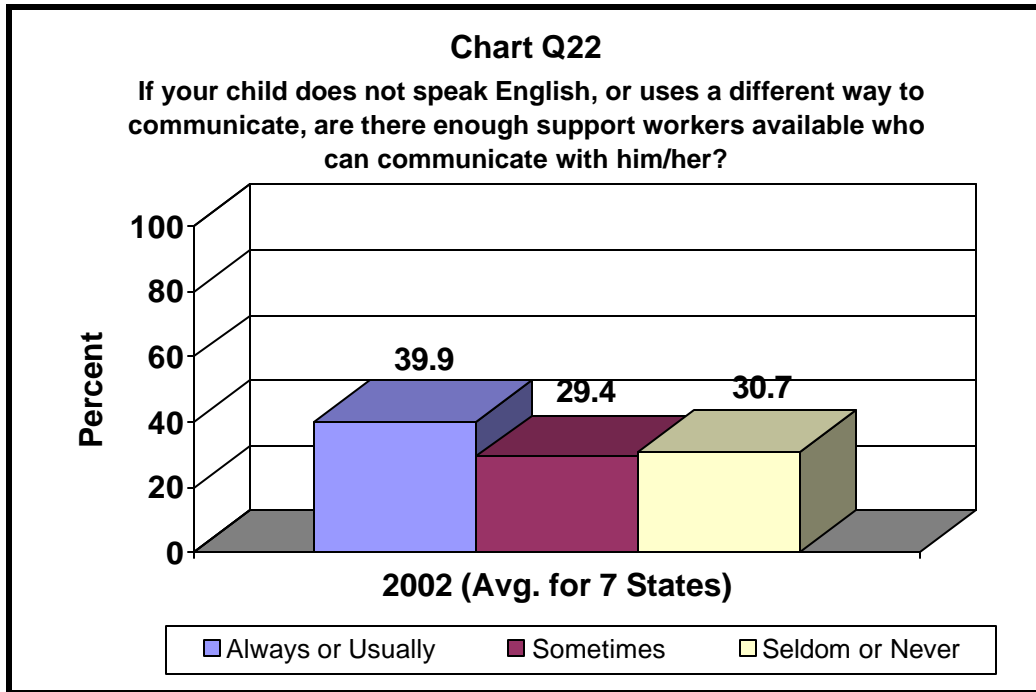


Table Q22					
If your child does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		42.6	35.1	22.3	94
CA-RCOC	↑↑	74.4	16.4	9.2	379
MA	↓	30.2	28.6	41.3	63
SC	↑↑	58.8	0.0	41.2	17
SD	↓↓	21.6	45.9	32.4	37
WA	↓↓	17.6	36.8	45.6	68
WY	↓	34.1	43.2	22.7	44
Total %		55.0	24.8	20.2	Total n = 702
State Average		39.9	29.4	30.7	Total n = 7

- ♦ Slightly more than one-half of respondents (57%) felt their child had access to the special equipment or accommodations needed.

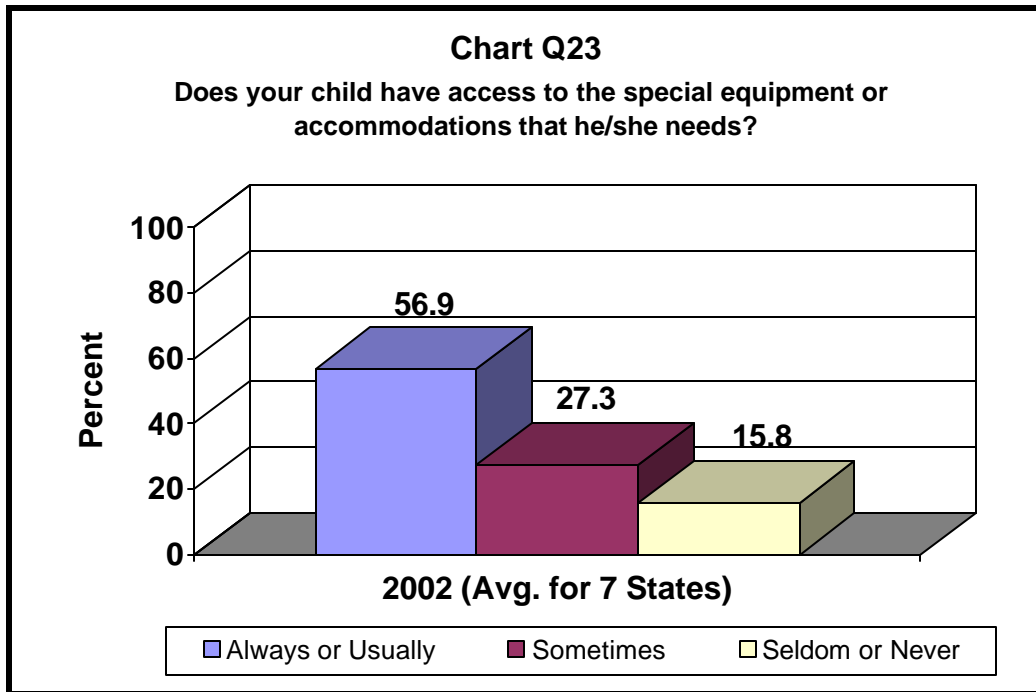


Table Q23					
Does your child have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		57.5	25.7	16.8	167
CA-RCOC		55.5	26.1	18.4	364
MA	↓	48.3	32.4	19.3	176
SC		60.5	16.3	23.3	43
SD	↑↑	69.6	26.1	4.3	115
WA	↓↓	44.6	36.5	18.9	249
WY	↑	62.2	28.3	9.4	127
Total %		54.7	28.9	16.4	Total n = 1241
State Average		56.9	27.3	15.8	Total n = 7

- ♦ The vast majority of respondents (90%) felt that they had access to health services for their child.

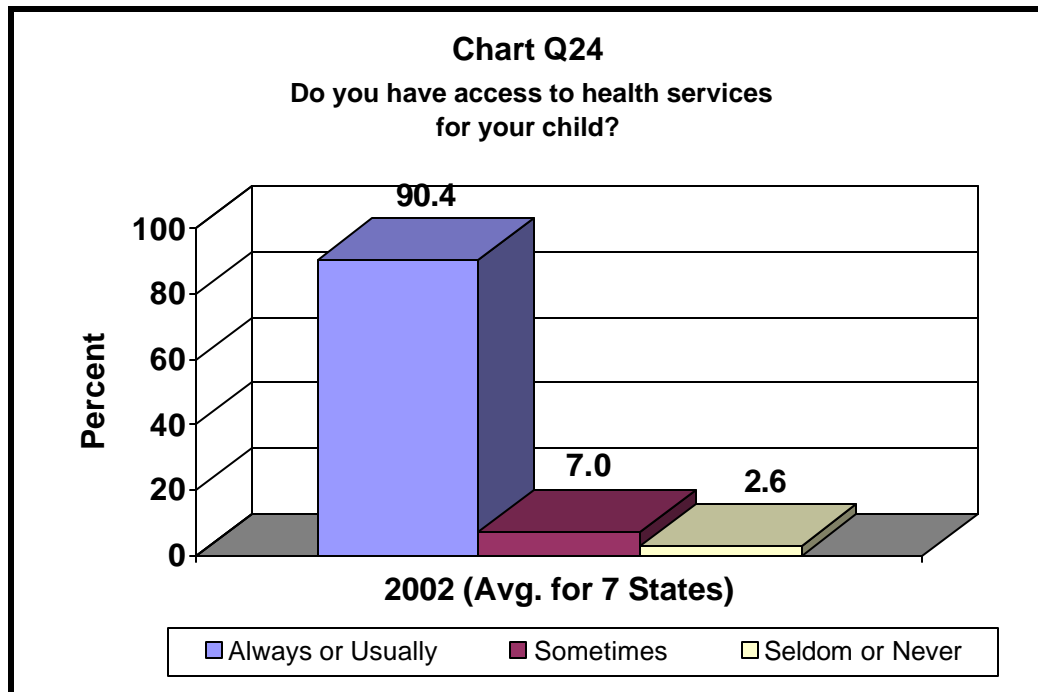


Table Q24 Do you have access to health services for your child?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		91.4	7.7	0.9	336
CA-RCOC	↓	81.0	8.3	10.7	674
MA		91.3	6.5	2.3	355
SC		88.8	9.2	2.0	98
SD	↑	96.5	3.5	0.0	171
WA		90.3	7.5	2.2	455
WY		93.5	6.5	0.0	184
Total %		88.5	7.3	4.2	Total n = 2273
State Average		90.4	7.0	2.6	Total n = 7

- ♦ Slightly fewer families (87%) felt they had access to appropriate dental services for their family member. These results were consistent across states.

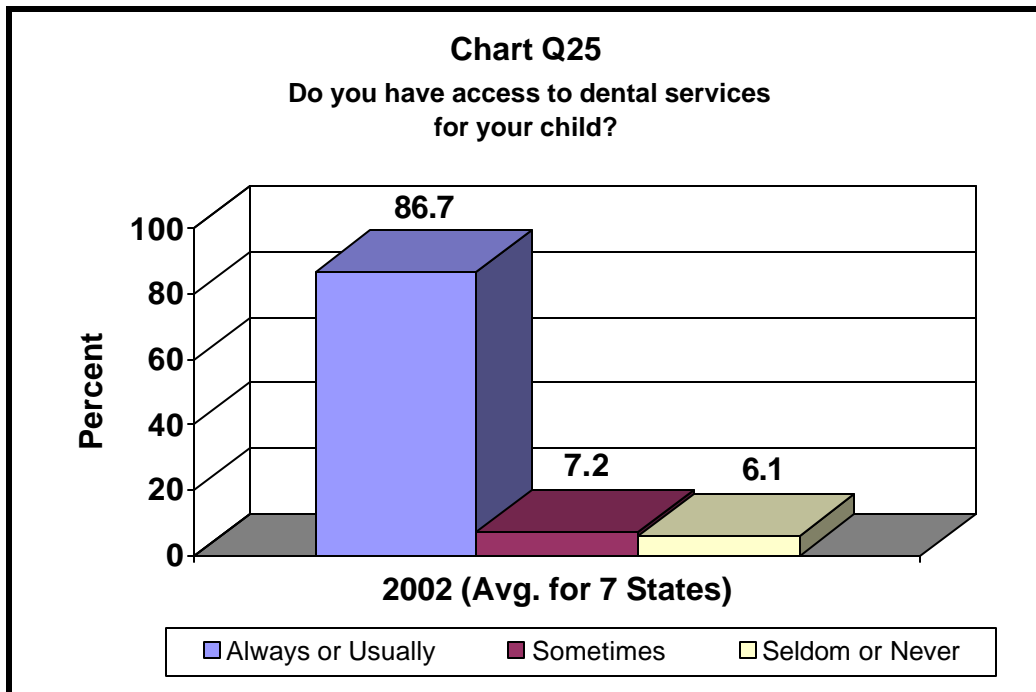


Table Q25 Do you have access to dental services for your child?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		87.1	7.3	5.7	317
CA-RCOC		83.1	6.3	10.6	780
MA		86.8	5.9	7.3	356
SC		90.5	6.3	3.2	95
SD		88.7	8.8	2.5	159
WA		85.5	6.9	7.6	448
WY		85.2	8.8	6.0	182
Total %		85.5	6.8	7.7	Total n = 2337
State Average		86.7	7.2	6.1	Total n = 7

- ◆ Nearly all respondents (91%) felt they had access to necessary medications for their child with a disability.

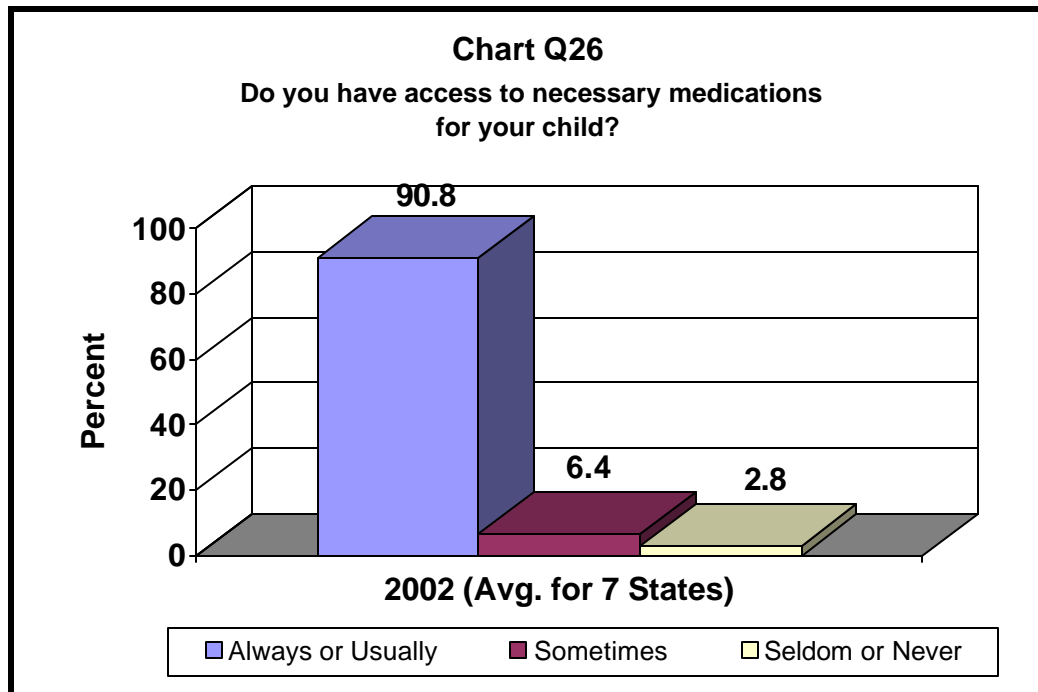


Table Q26					
Do you have access to necessary medications for your child?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		88.0	10.4	1.6	316
CA-RCOC	↓	82.4	10.1	7.5	783
MA		91.7	5.9	2.4	337
SC		89.7	4.1	6.2	97
SD	↑	98.2	1.8	0.0	165
WA		91.0	6.9	2.1	435
WY		94.3	5.7	0.0	174
Total %		88.5	7.8	3.8	Total n = 2307
State Average		90.8	6.4	2.8	Total n = 7

- ♦ Three-quarters of respondents (76%) indicated that frequent changes in support staff were a problem for their family at least some of the time.

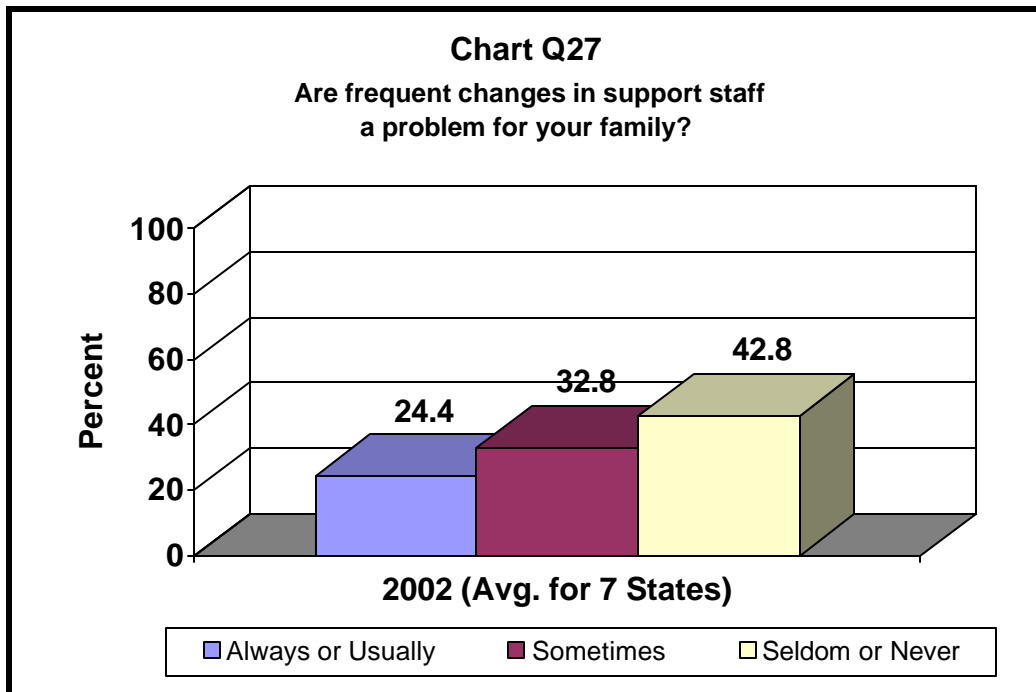


Table Q27 Are frequent changes in support staff a problem for your family?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		24.2	34.7	41.1	285
CA-RCOC	↓↓↓	47.3	28.2	24.4	712
MA		19.9	34.7	45.4	251
SC	↑	25.6	25.6	48.7	78
SD	↑↑↑	11.8	31.5	56.7	127
WA		23.8	34.8	41.5	328
WY		18.3	40.2	41.5	164
Total %		30.8	32.2	37.0	Total n = 1945
State Average		24.4	32.8	42.8	Total n = 7

- ♦ The vast majority of families (87%) felt that support staff, in general, were respectful and courteous.

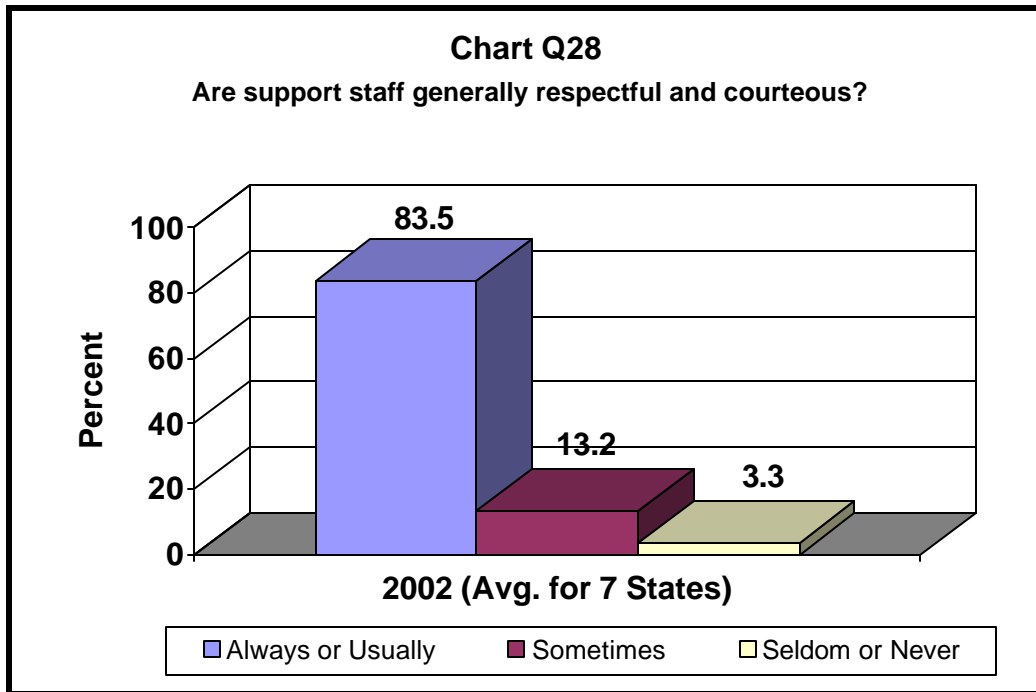


Table Q28					
Are support staff generally respectful and courteous?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		85.5	13.0	1.5	330
CA-RCOC	↓↓	64.1	23.1	12.8	713
MA		86.3	11.9	1.8	278
SC		82.1	14.7	3.2	95
SD	↑↑	93.7	5.0	1.3	159
WA		86.6	12.3	1.1	357
WY		86.4	12.4	1.1	177
Total %		79.1	15.6	5.3	Total n = 2109
State Average		83.5	13.2	3.3	Total n = 7

Choice and Control

- ♦ Across the states, on average, 52% of respondents chose the agencies or providers who work with their families. In Wyoming, this percentage was considerably higher, with 78% or more of families choosing their service providers. In South Dakota, Arizona and Orange County, California, considerably fewer families chose their providers/agencies.

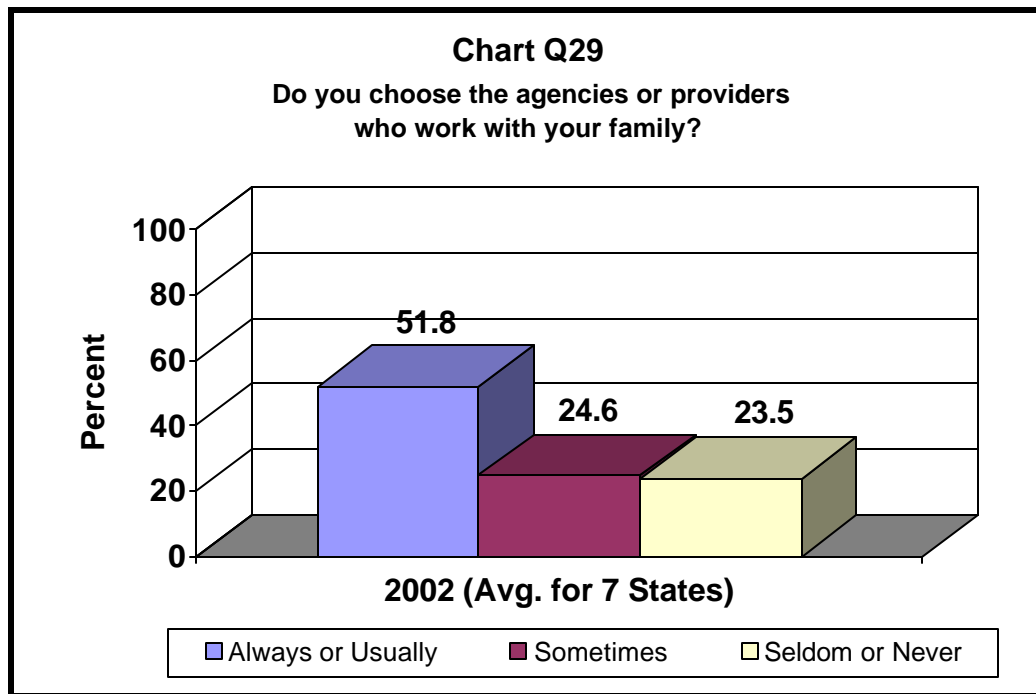


Table Q29 Do you choose the agencies or providers who work with your family?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	39.6	30.7	29.7	313
CA-RCOC	↓↓↓	35.4	28.5	36.2	622
MA		53.8	24.7	21.5	279
SC		52.9	22.4	24.7	85
SD	↓↓↓	41.5	27.9	30.6	147
WA	↑	61.6	19.2	19.2	406
WY	↑↑↑	78.1	19.1	2.7	183
Total %		48.8	25.3	25.9	Total n = 2035
State Average		51.8	24.6	23.5	Total n = 7

- ♦ While 52% of respondents typically chose their family's provider agency, only 42% (on average) typically chose the support workers who worked directly with their family. Once again, the results were considerably higher in Wyoming.

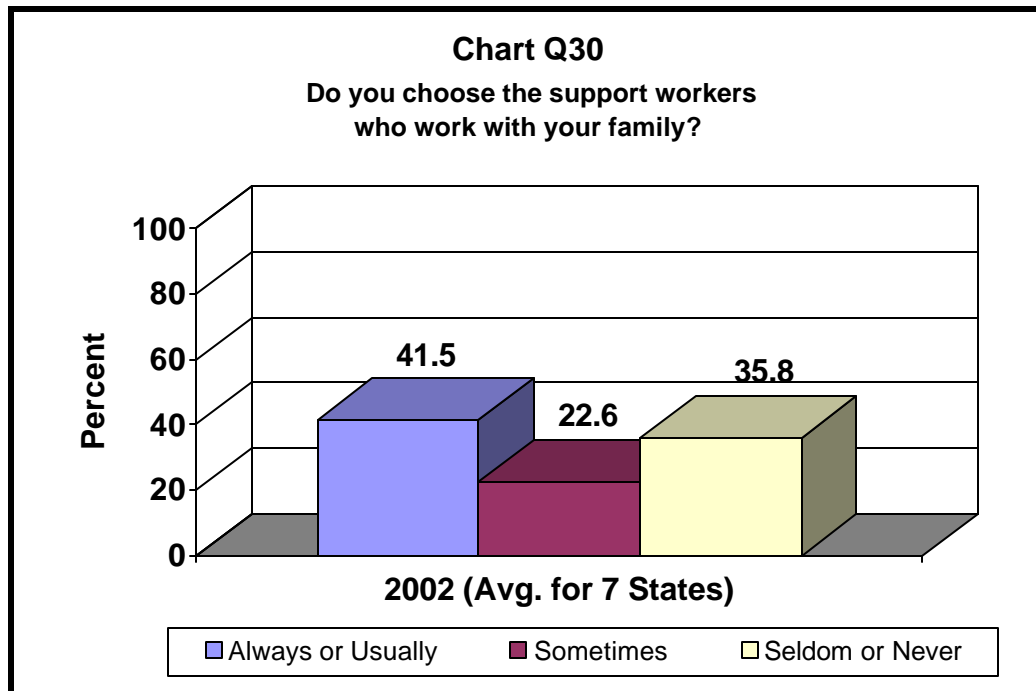


Table Q30 Do you choose the support workers who work with your family?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓	31.9	24.6	43.5	285
CA-RCOC	↓↓	25.2	20.4	54.5	604
MA		41.0	27.6	31.3	268
SC	↑	46.8	21.5	31.6	79
SD	↓↓	30.7	26.3	43.1	137
WA		38.5	19.6	41.9	358
WY	↑↑	76.7	18.3	5.0	180
Total %		37.0	22.1	40.8	Total n = 1911
State Average		41.5	22.6	35.8	Total n = 7

- ♦ Among all respondents, about one-third (37%) had control or input over the hiring and management of their support staff, and an additional 16% indicated they had this control sometimes. Forty-seven percent, however, did not have any input or control over the hiring or management of their family's support staff.

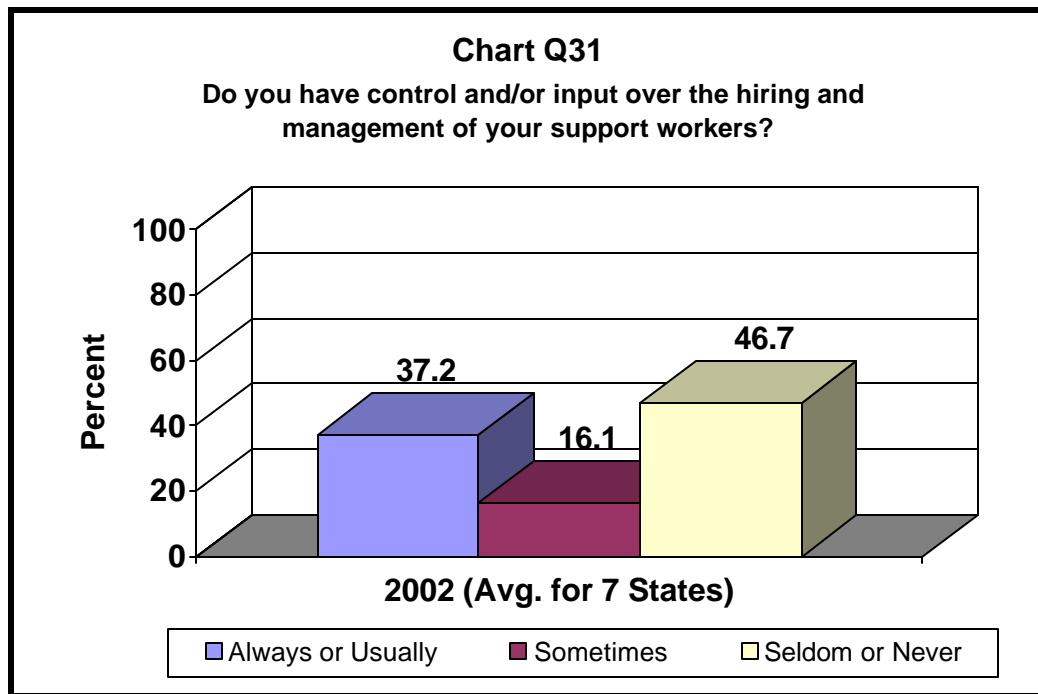


Table Q31 Do you have control and/or input over the hiring and management of your support workers?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓ ↓	26.8	16.7	56.5	239
CA-RCOC	↓ ↓	25.5	17.5	57.1	487
MA	↑	44.6	20.1	35.3	224
SC	↓	28.6	12.7	58.7	63
SD	↓ ↓	18.8	9.4	71.8	117
WA	↑ ↑	54.7	16.0	29.3	331
WY	↑ ↑	61.1	20.4	18.5	157
Total %		37.4	16.9	45.7	Total n = 1618
State Average		37.2	16.1	46.7	Total n = 7

- ♦ While only 53% of respondents had at least some control over the hiring or management of their support workers, 83% wanted this type of control.

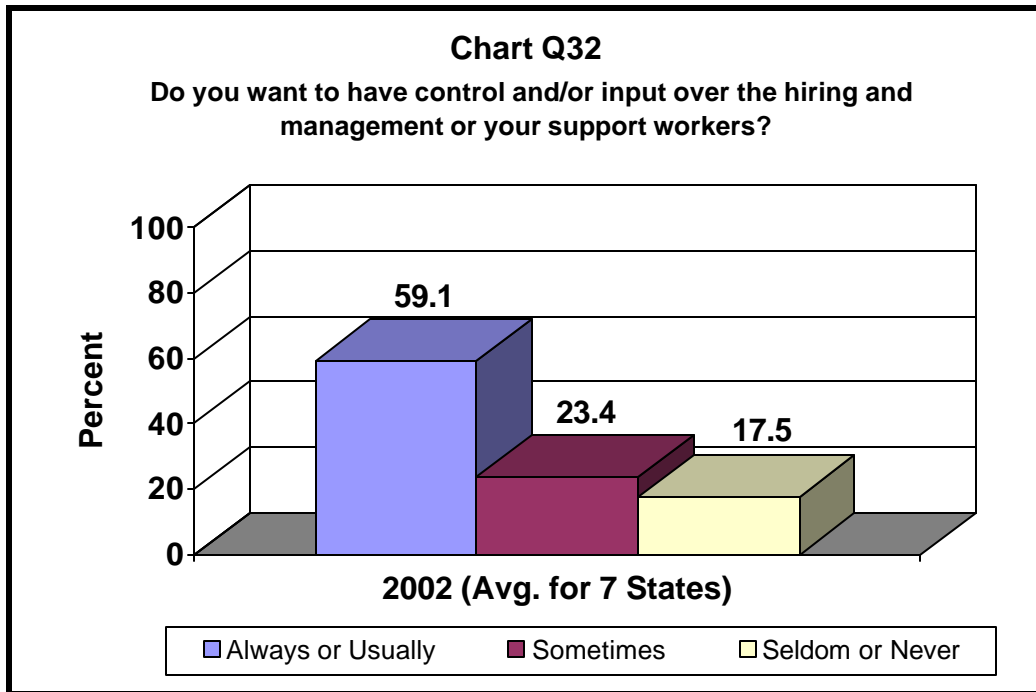


Table Q32					
Do you want to have control and/or input over the hiring and management of your support workers?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		54.9	28.7	16.4	244
CA-RCOC		55.3	25.3	19.3	450
MA	↑	67.2	19.5	13.3	241
SC	↓	52.6	21.1	26.3	57
SD	↓↓	43.2	29.7	27.0	111
WA	↑	67.4	19.2	13.5	334
WY	↑↑	73.0	20.4	6.6	152
Total %		60.6	23.3	16.3	Total n = 1589
State Average		59.1	23.4	17.5	Total n = 7

- ◆ Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses. For this reason, states may notice higher responses in this category than in previous years.
- ◆ Only one-quarter (25%) of respondents or their family members knew how much money was spent by the MR/DD agency on behalf of their family member. Two-thirds (65%), however, had little or no idea.

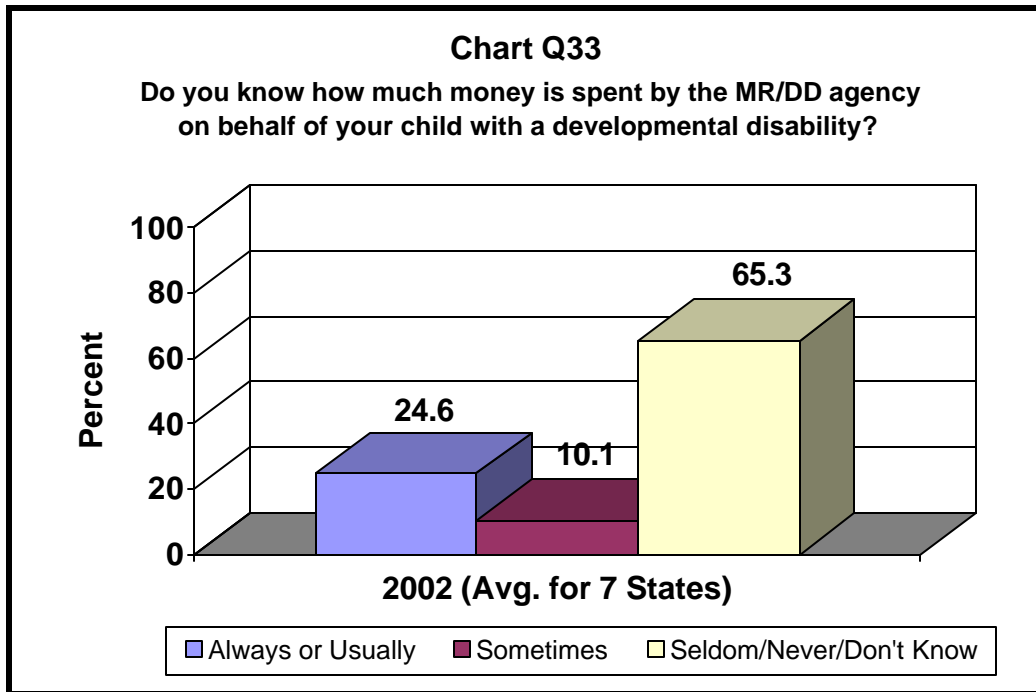


Table Q33 Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?					
State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ	↓↓↓	12.0	11.7	76.2	332
CA-RCOC	↓↓↓	14.5	6.6	78.9	800
MA	↑	29.6	9.1	61.3	328
SC	↓↓↓	14.3	2.0	83.7	98
SD		22.2	16.7	61.1	162
WA	↑	31.1	11.9	57.0	453
WY	↑↑	48.4	12.6	39.0	182
Total %		22.6	9.7	67.7	Total n = 2355
State Average		24.6	10.1	65.3	Total n = 7

- ♦ Overall, slightly more than half of the families surveyed (58%) had at least some decision-making authority over how the money available to their family member with disabilities by the MR/DD agency was spent. Forty-two percent, however, did not. Results varied considerably from state to state.

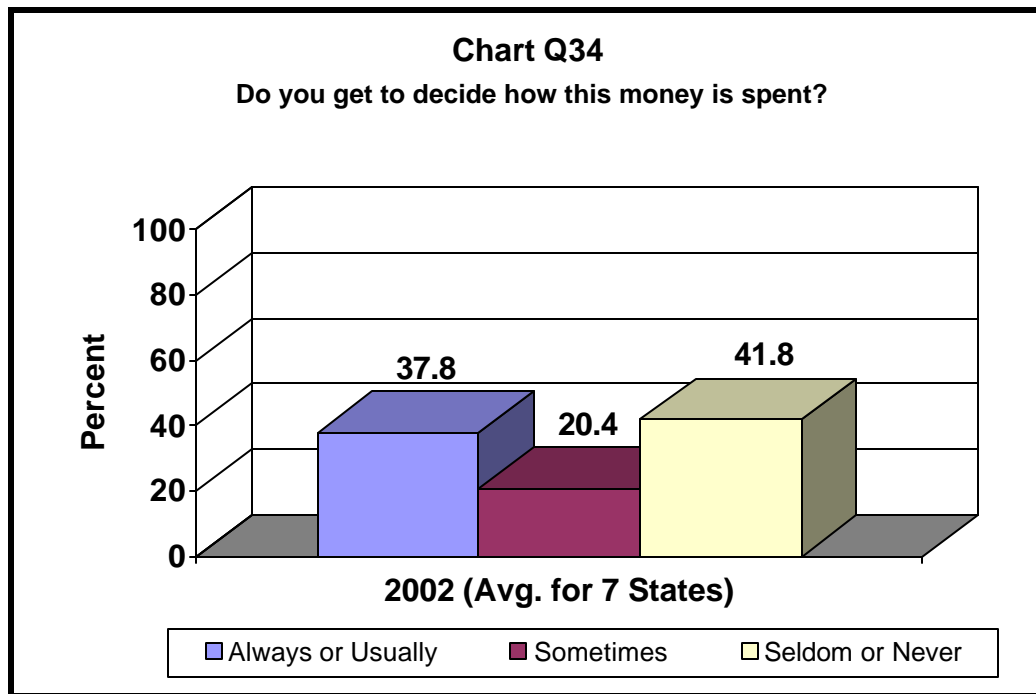


Table Q34 Do you get to decide how this money is spent?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	7.6	12.8	79.6	211
CA-RCOC	↓↓↓	27.0	13.6	59.4	456
MA	↑↑↑	53.9	21.0	25.1	243
SC	↓↓↓	23.6	12.7	63.6	55
SD	↑↑↑	49.6	27.6	22.8	127
WA		39.4	31.0	29.6	358
WY	↑↑↑	63.3	24.1	12.7	158
Total %		36.5	20.6	42.9	Total n = 1608
State Average		37.8	20.4	41.8	Total n = 7

Community Connections

- ♦ On average, one-quarter of respondents (26%) felt that planning or support staff were regularly available to help them use typical community supports (e.g., from a local health club, church or recreation activities) if desired. Another 29% said that staff were sometimes helpful, but 45% stated that planning and support staff were seldom or never helpful in connecting their family members to typical community supports or resources.

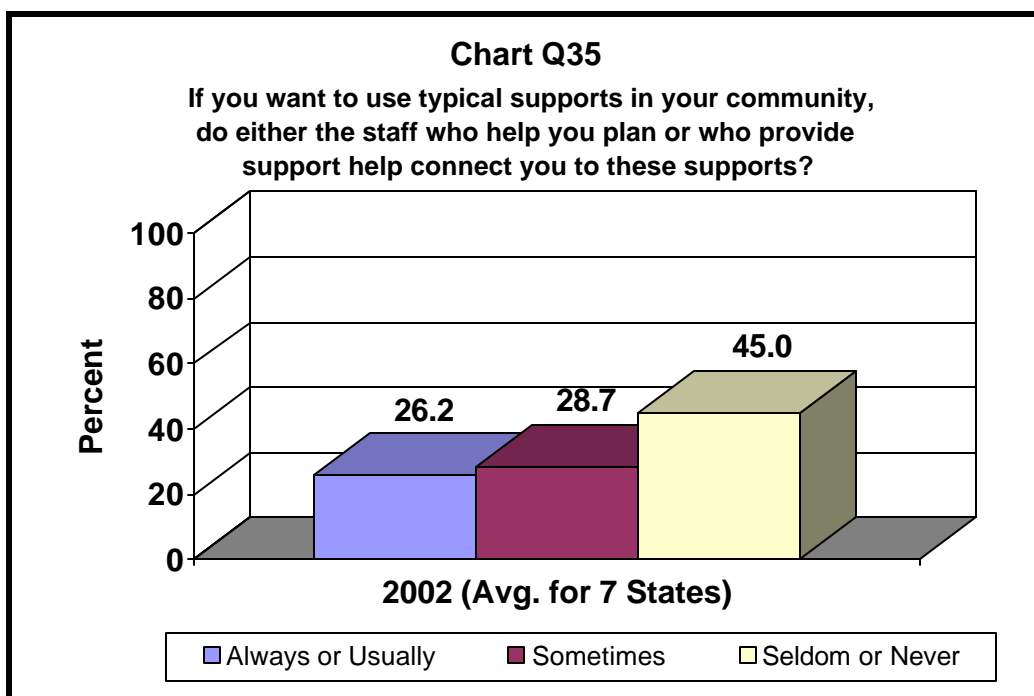


Table Q35 If you want to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		26.4	26.9	46.8	216
CA-RCOC		26.6	27.3	46.1	534
MA	↓	21.0	24.7	54.3	243
SC	↑	34.5	22.4	43.1	58
SD		26.5	36.7	36.7	98
WA	↓	19.6	27.7	52.7	347
WY		29.0	35.5	35.5	138
Total %		24.7	28.0	47.2	Total n = 1634
State Average		26.2	28.7	45.0	Total n = 7

- Overall, there was a split between respondents who indicated that staff helped them figure out how family, friends or neighbors could provide some of the families' needed supports (37% say yes, 39% say no, and the remaining 23% say it occasionally happens).

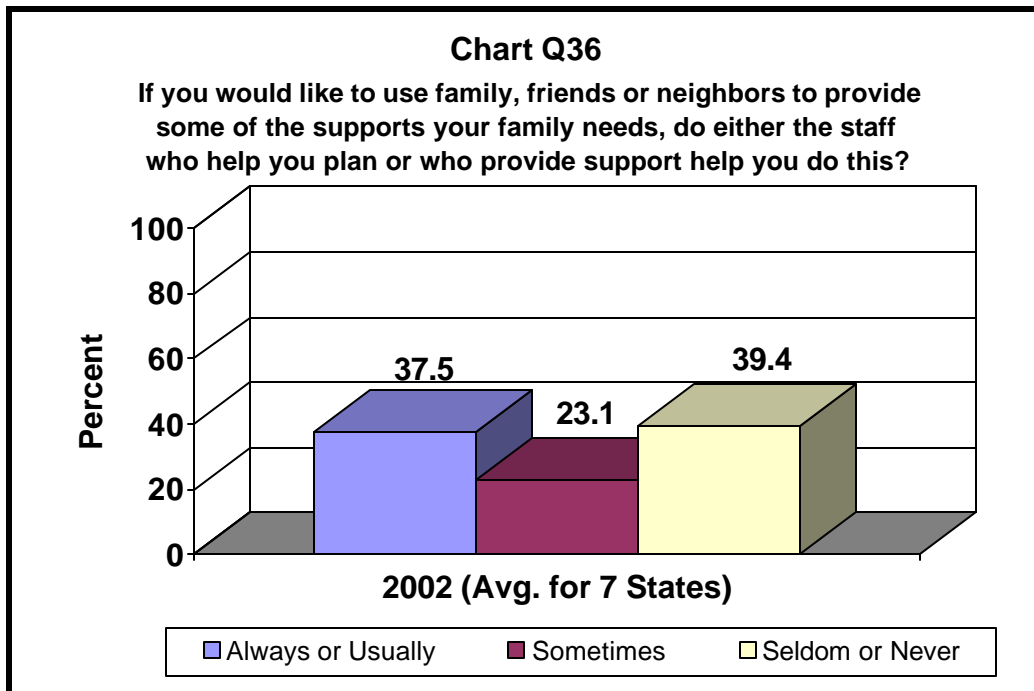


Table Q36					
If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↓↓↓	24.3	22.4	53.3	214
CA-RCOC	↓	32.1	24.6	43.4	505
MA	↓↓↓	27.4	22.6	50.0	230
SC	↑↑↑	53.0	18.2	28.8	66
SD	↑↑↑	52.2	24.8	23.0	113
WA	↓	32.5	27.1	40.4	354
WY		40.7	22.2	37.0	135
Total %		33.5	24.1	42.4	Total n = 1617
State Average		37.5	23.1	39.4	Total n = 7

- ♦ Only 73% of families felt their family member always or usually had access to community activities. 26% stated their family member seldom or never had access to the community.

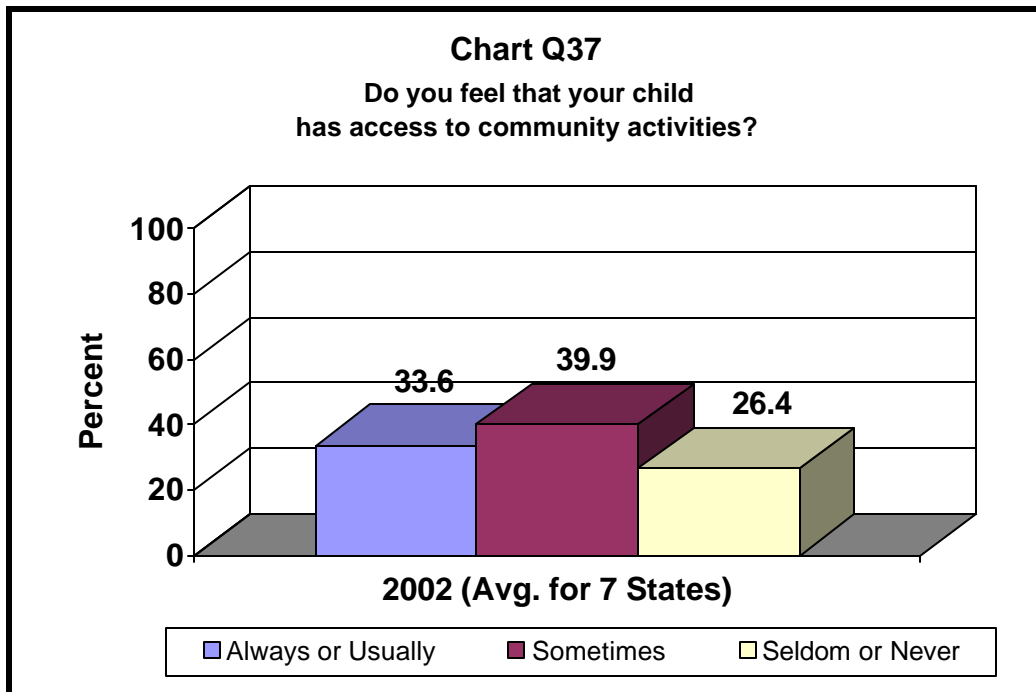


Table Q37 Do you feel that your child has access to community activities?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑	40.6	37.1	22.4	286
CA-RCOC		30.7	38.2	31.0	670
MA	↓ ↓	21.6	43.5	34.9	347
SC	↑ ↑	47.7	29.5	22.7	88
SD		30.5	42.9	26.6	154
WA	↓	27.2	41.5	31.2	426
WY		37.1	46.6	16.3	178
Total %		31.1	40.3	28.7	Total n = 2149
State Average		33.6	39.9	26.4	Total n = 7

- ♦ While 34% had regular access to community activities, only 20% of children regularly participated in them. Forty-one percent of respondents said that their child seldom or never participated in community activities or events ~ and these results were consistent across the states.

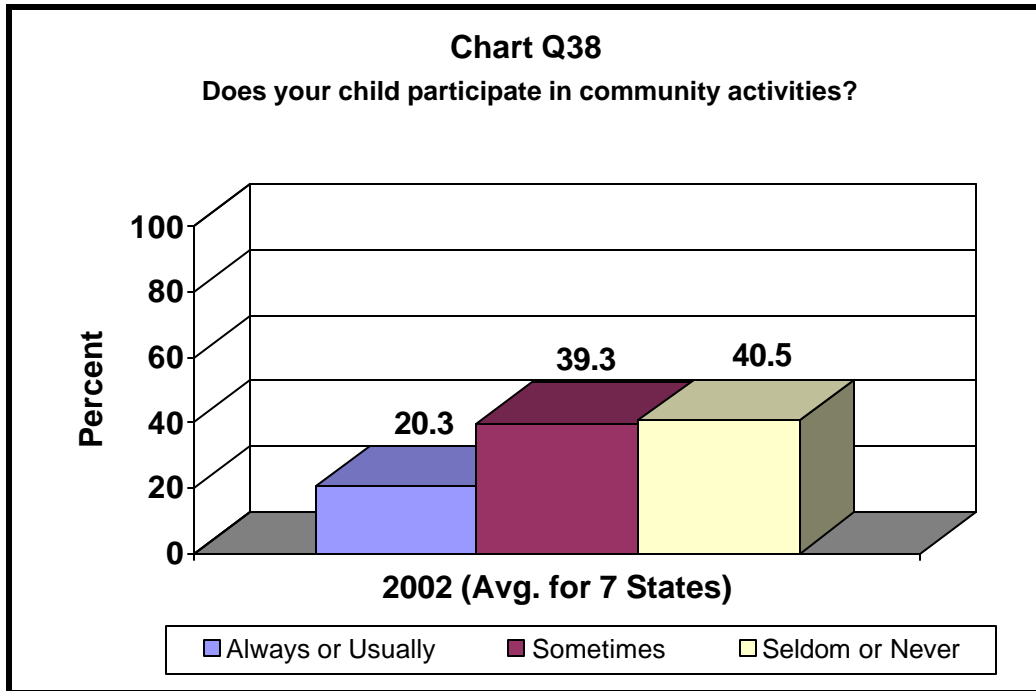


Table Q38 Does your child participate in community activities?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		23.7	35.2	41.1	304
CA-RCOC		19.2	37.7	43.1	677
MA		18.4	35.7	46.0	359
SC		23.9	34.1	42.0	88
SD		16.9	40.3	42.9	154
WA		16.8	41.8	41.4	435
WY		23.0	50.0	27.0	178
Total %		19.5	38.9	41.6	Total n = 2195
State Average		20.3	39.3	40.5	Total n = 7

- ♦ About half (52%) of respondents' children regularly spend time with children who do not have disabilities ~ which leaves the other half (48%) who only spend some or little time with children without disabilities.

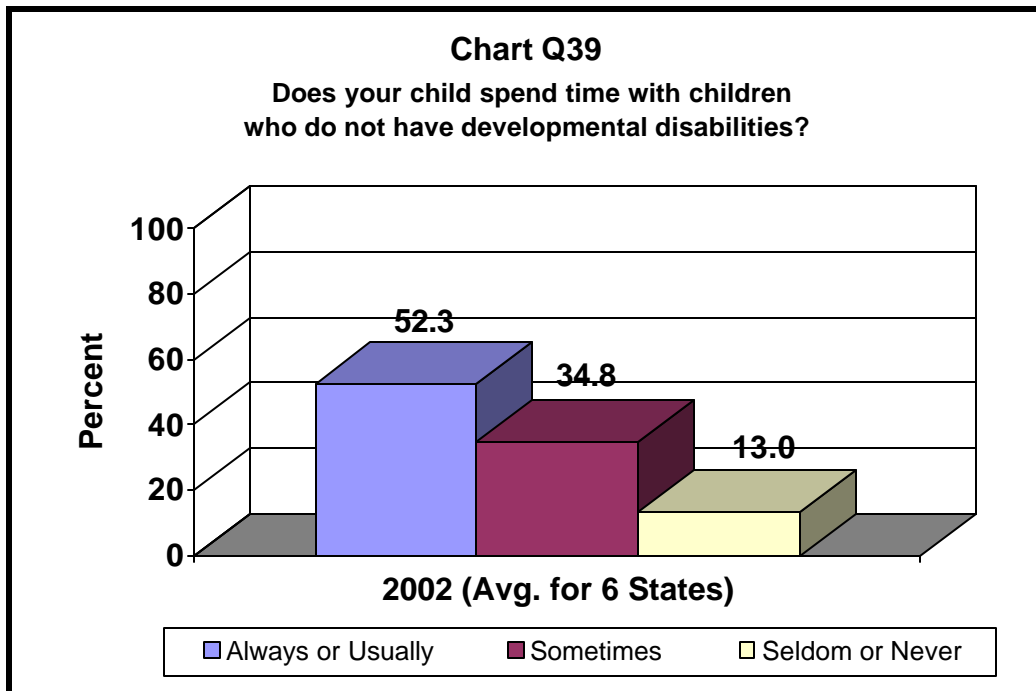


Table Q39					
Does your child spend time with children who do not have developmental disabilities?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ	↑↑	63.1	28.3	8.6	339
CA-RCOC		52.6	33.9	13.5	814
MA	↓↓	41.9	39.4	18.6	360
SC		* Question not asked			
SD		57.2	31.9	10.8	166
WA		47.6	37.5	14.9	464
WY		51.1	37.5	11.4	184
Total %		51.7	34.8	13.5	Total n = 2327
State Average		52.3	34.8	13.0	Total n = 7

Outcomes and Satisfaction with Services and Supports

- Overall, 61% were always or usually satisfied with the services and supports they received. 32% were somewhat satisfied, and 7% were seldom or never satisfied.

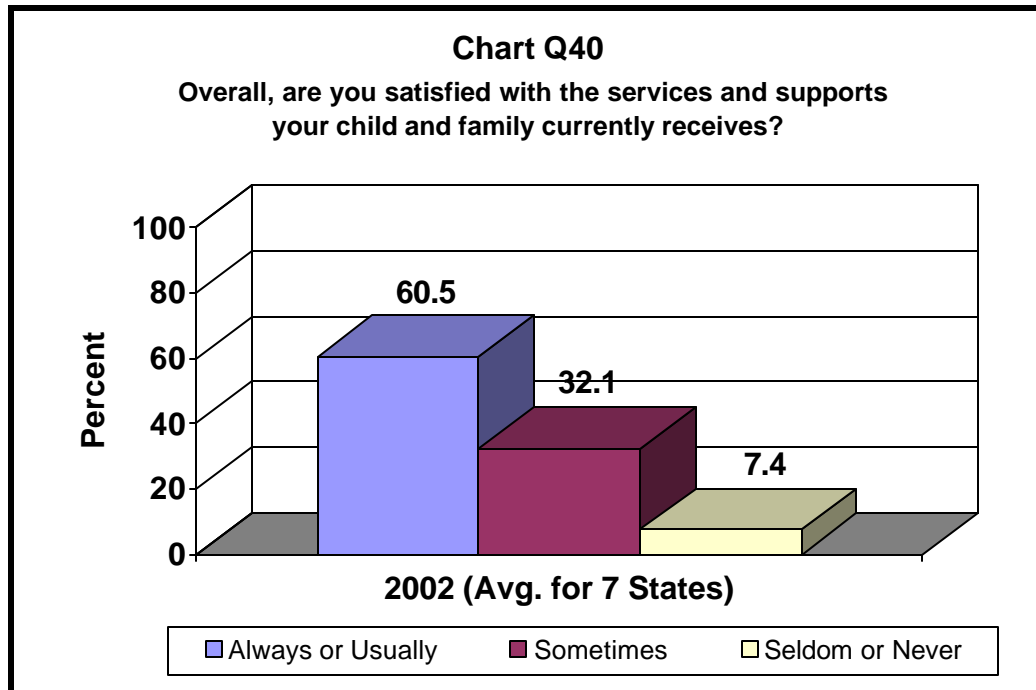


Table Q40					
Overall, are you satisfied with the services and supports your child and family currently receives?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		62.2	33.6	4.2	336
CA-RCOC		56.5	33.5	10.0	811
MA	↓↓	41.4	40.8	17.8	331
SC	↑	65.9	27.5	6.6	91
SD	↑↑	82.6	16.2	1.2	167
WA	↓↓	47.6	43.4	9.0	456
WY	↑	67.2	29.5	3.3	183
Total %		56.5	34.7	8.8	Total n = 2375
State Average		60.5	32.1	7.4	Total n = 7

- ◆ Please note, due to this question's wording, "Don't Know" responses were interpreted to be similar in meaning and therefore included with the "Seldom or Never" responses. For this reason, states may notice higher responses in this category than in previous years.
- ◆ On average, only 37% of respondents knew about their agency's grievance process, while 51% had little or no familiarity with the process for lodging a complaint.

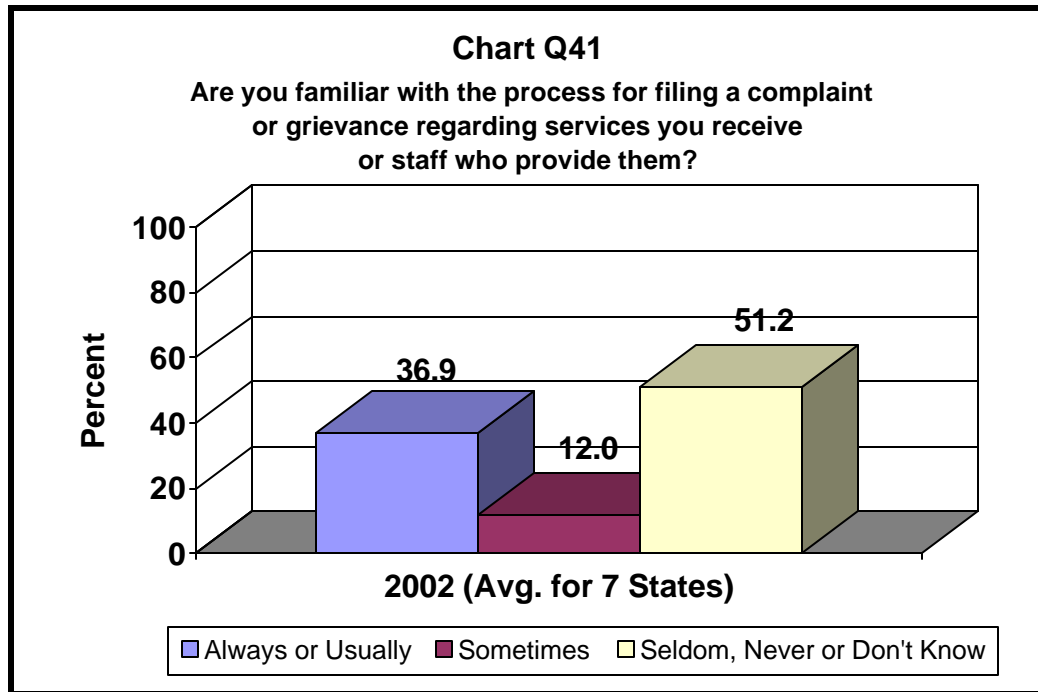
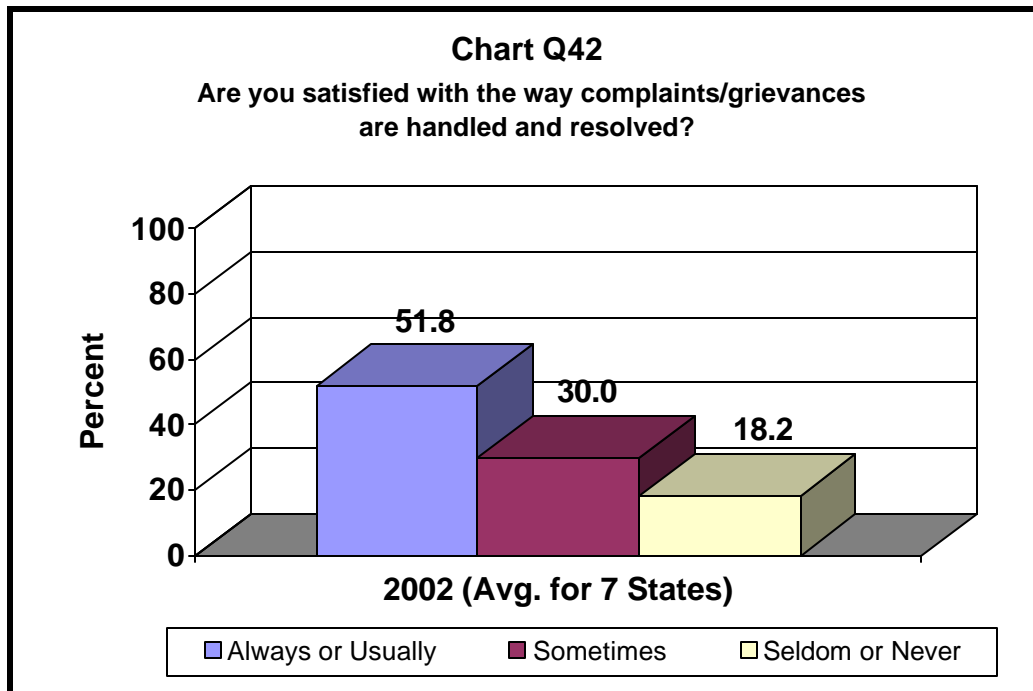


Table Q41 Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?					
State		Always or Usually	Sometimes	* Seldom, Never or Don't Know	n
AZ	↑	42.1	9.2	48.7	316
CA-RCOC		40.4	15.2	44.4	789
MA	↓	28.8	5.7	65.5	316
SC	↓	31.6	19.0	49.4	79
SD	↑	43.9	12.1	43.9	157
WA	↓ ↓	26.9	10.8	62.3	424
WY	↑	44.4	11.7	43.9	180
Total %		36.8	11.9	51.4	Total n = 2261
State Average		36.9	12.0	51.2	Total n = 7

- ♦ A slight majority of respondents (52%) were satisfied with the way complaints or grievances were handled and resolved by their state agency. The remaining 48%, however, were either not satisfied, or only sometimes satisfied with how these matters were resolved.



♦

Table Q42 Are you satisfied with the way complaints/grievances are handled and resolved?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		50.4	29.4	20.2	119
CA-RCOC		49.4	33.2	17.4	328
MA		47.4	28.9	23.7	76
SC		54.3	26.1	19.6	46
SD	↑↑	65.4	25.0	9.6	52
WA	↓	44.7	32.7	22.7	150
WY		50.8	34.9	14.3	63
Total %		49.9	31.4	18.7	Total n = 834
State Average		51.8	30.0	18.2	Total n = 7

- ♦ Sixty-nine percent of families felt that services and supports have made a positive difference in their lives. Only 7% stated that they seldom felt this way.

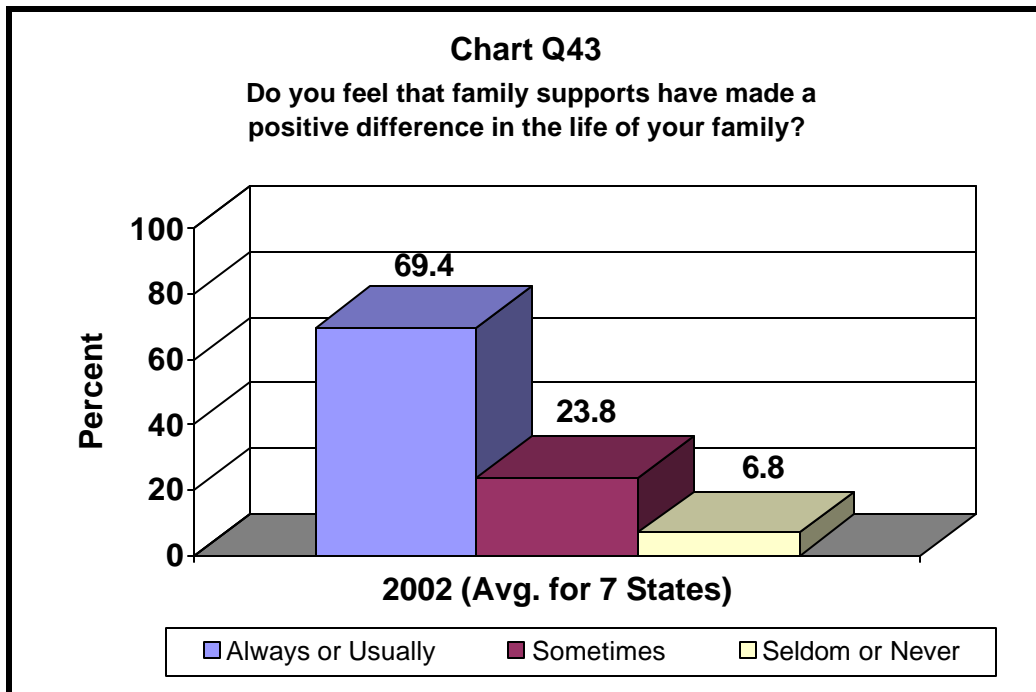


Table Q43 Do you feel that family supports have made a positive difference in the life of your family?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		67.0	27.8	5.2	306
CA-RCOC	↓	59.9	30.9	9.3	713
MA	↓↓	56.4	29.8	13.8	319
SC		71.4	20.9	7.7	91
SD	↑↑	92.2	7.2	0.6	167
WA		67.1	24.7	8.2	438
WY		71.8	25.4	2.8	177
Total %		65.7	26.4	7.9	Total n = 2211
State Average		69.4	23.8	6.8	Total n = 7

- Nearly all families (91%) felt that family supports improved, to some extent, their ability to care for their child.

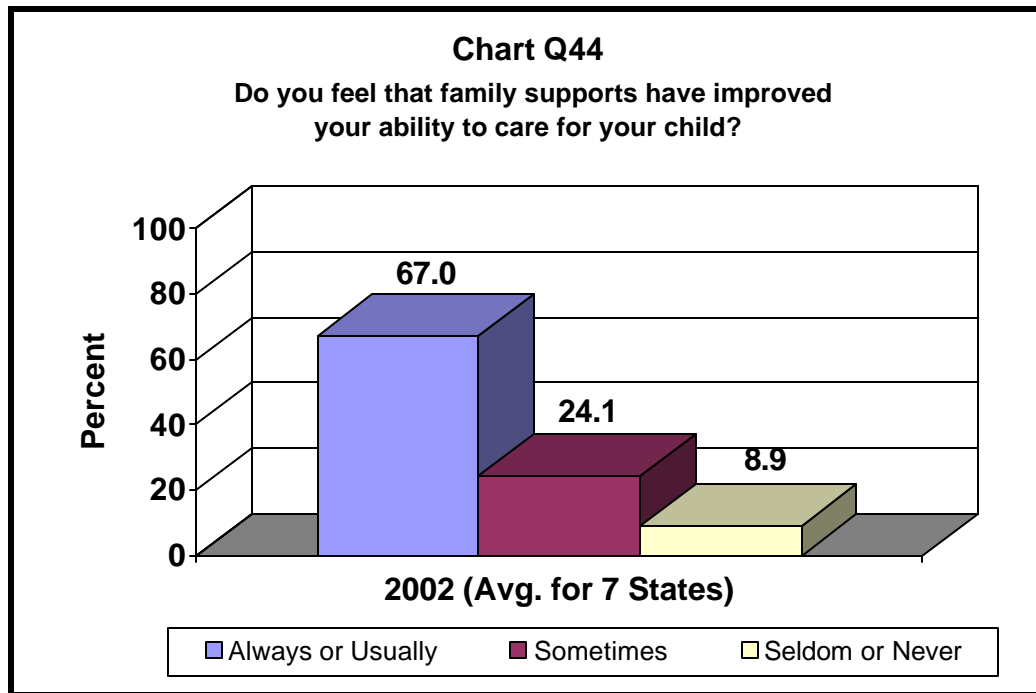


Table Q44					
Do you feel that family supports have improved your ability to care for your child?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		67.9	23.9	8.2	305
CA-RCOC	↓	58.2	31.4	10.3	716
MA	↓↓	54.3	27.8	18.0	317
SC		64.8	26.1	9.1	88
SD	↑↑	89.2	7.8	3.0	166
WA		63.8	25.6	10.6	442
WY		70.6	26.0	3.4	177
Total %		63.7	26.3	10.0	Total n = 2211
State Average		67.0	24.1	8.9	Total n = 7

- ♦ Three-fourths (73%) of respondents indicated that services have made a difference in helping them keep their child at home.

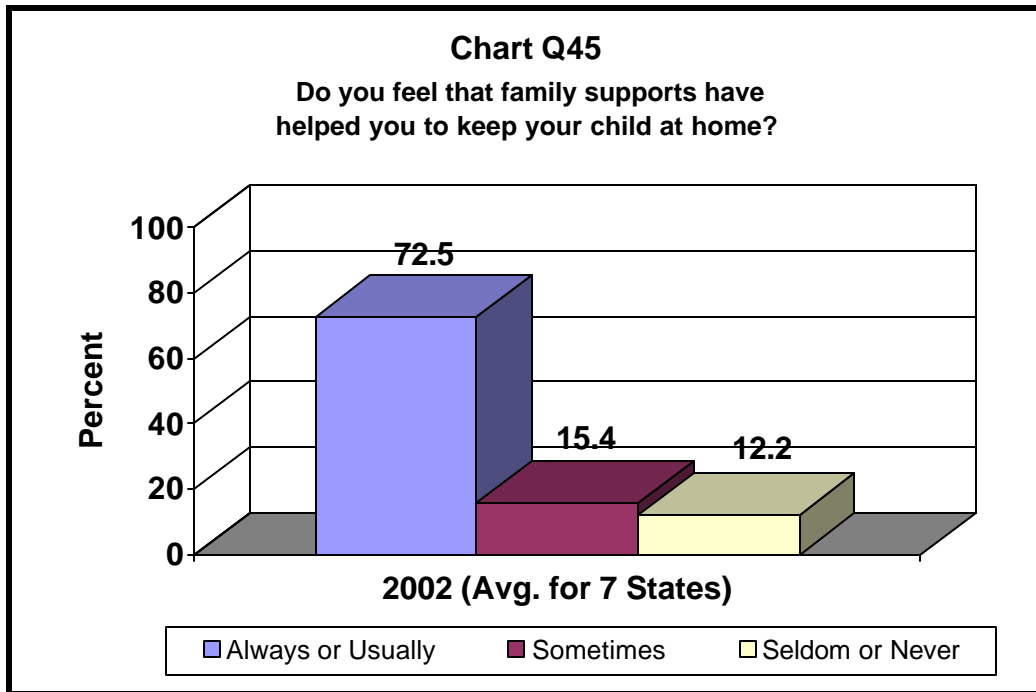


Table Q45					
Do you feel that family supports have helped you to keep your child at home?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		73.1	15.8	11.1	253
CA-RCOC	↓	64.2	19.7	16.1	654
MA	↓↓	61.7	14.5	23.8	269
SC	↑	77.9	11.7	10.4	77
SD	↑↑	83.6	10.3	6.2	146
WA		69.1	15.1	15.8	392
WY	↑	77.8	20.4	1.9	162
Total %		69.1	16.6	14.3	Total n = 1953
State Average		72.5	15.4	12.2	Total n = 7

- ♦ Eighty-four percent of respondents felt that their family member was usually happy.

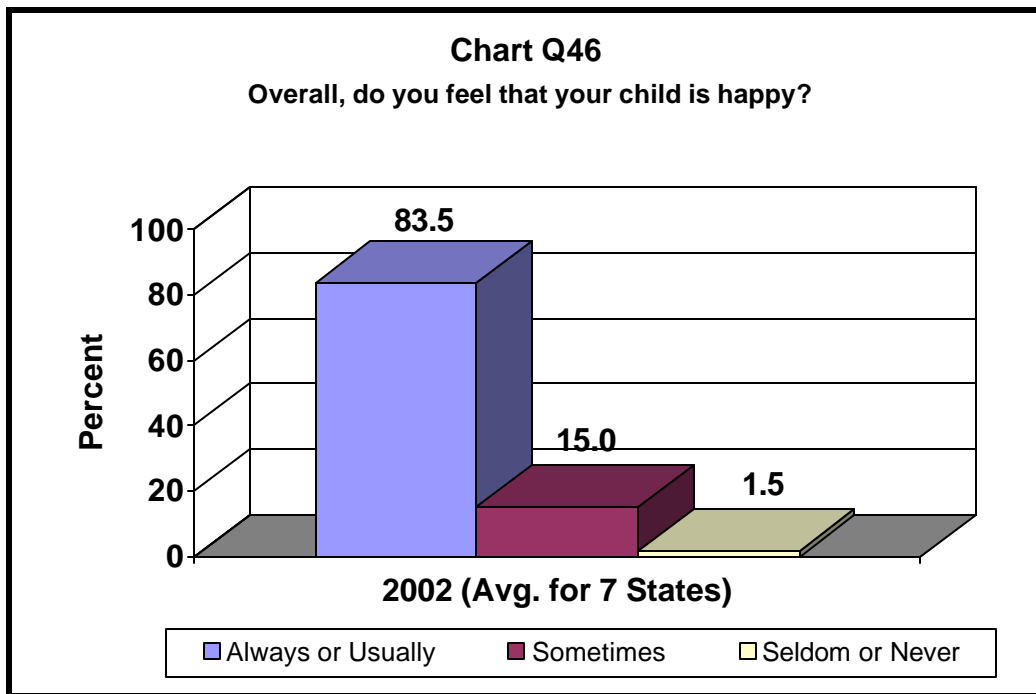


Table Q46 Overall, do you feel that your child is happy?					
State		Always or Usually	Sometimes	Seldom or Never	n
AZ		86.4	12.7	0.9	338
CA-RCOC	↓	78.2	19.6	2.2	834
MA		78.7	18.0	3.4	256
SC		87.0	10.9	2.2	92
SD		88.2	11.8	0.0	170
WA		80.0	18.8	1.3	469
WY		86.3	13.1	0.5	183
Total %		81.4	16.9	1.7	Total n = 2440
State Average		83.5	15.0	1.5	Total n = 7

Aggregate Results & State Trends

Above, the findings are displayed question by question. In this section, we look at survey findings by each categorical area of questioning (i.e., information and planning, access and delivery of services, choice and control, community connections, and overall satisfaction).

For each of these categories, there is a CHART that displays the State Average ~ indicating the average percentage, across states, of respondents who answered each question with an “always or usually” response. In nearly all cases, the higher this response, the more satisfied the respondents were with their supports.

For each category, there is also a TABLE that looks at the arrows (i.e., \uparrow and \downarrow) of the previous Tables, with single arrows representing state results $\pm 5\%$ from the state average, and double arrows ($\uparrow\uparrow$ and $\downarrow\downarrow$) representing $\pm 10\%$ from the state average.

This compilation of results (up arrows minus down arrows) provides a crude overview of trends, across states and within topic groupings (e.g., information and planning, choice and control), illustrating how states measured up, overall, against the state averages.

As a review, the first chart illustrates state averages, and the table that follows illustrates how states compared to these state averages.

Information and Planning

- ♦ In South Carolina, South Dakota and Wyoming, responses to information and planning questions were generally above the overall state average. In Massachusetts and Washington, results were generally below the state average.

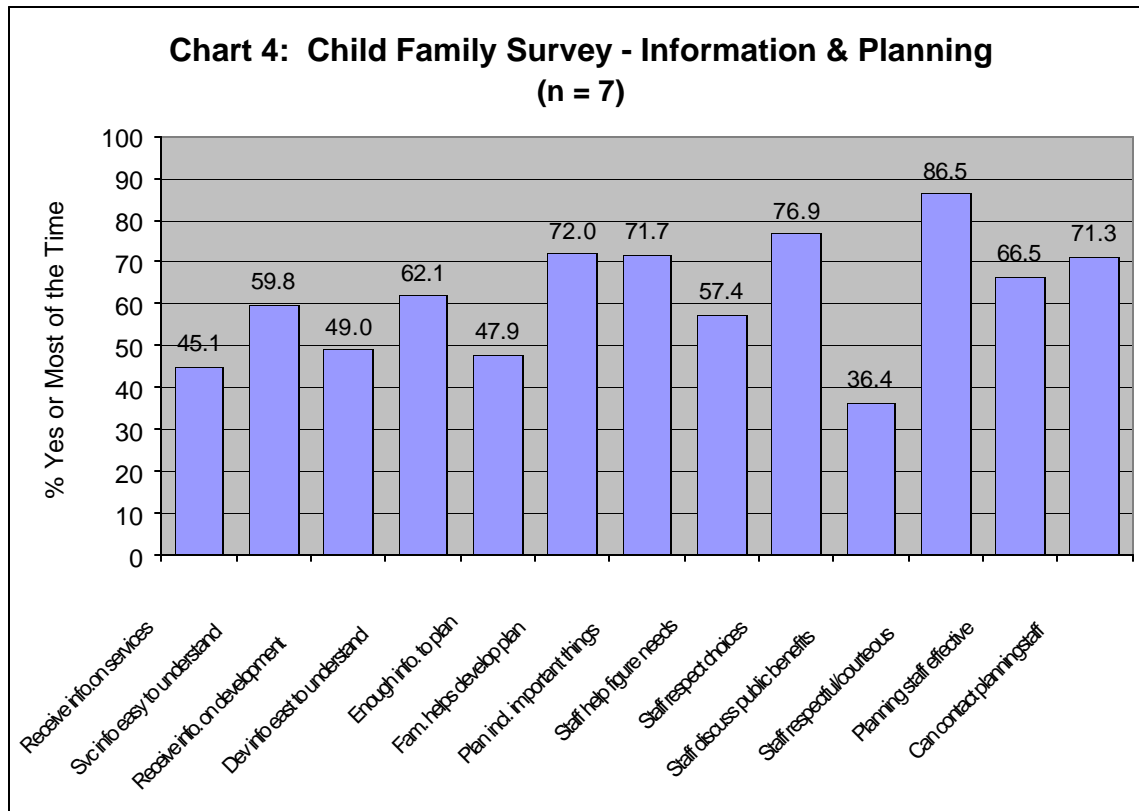


Table 17 Trends in Responses Above & Below State Average Information & Planning														
State	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Net Sum
AZ			↑↑	↑↑										4
CA-RCOC	↑↑	↑	↓			↓	↓↓	↓↓				↓		-4
MA	↓↓				↓↓	↓↓		↓↓	↓	↓↓		↓↓	↓	-14
SC			↑		↑↑			↑↑		↑↑		↑		8
SD	↑↑	↑↑			↑↑	↑	↑↑	↑↑	↑	↑	↑	↑↑	↑↑	18
WA	↓↓	↓↓	↓↓	↓↓	↓↓	↓	↓↓	↓↓	↓	↓		↓	↓↓	-20
WY		↓			↑	↑↑	↑↑	↑↑				↑	↑	8

Access and Delivery of Services

- ♦ In South Carolina and South Dakota, responses to access and delivery of services questions were generally above the overall state average. In Massachusetts and Washington, results were generally below the state average. Note that Question 18 is considered a “neutral question”, and therefore, up and down arrows were not used in the calculation of state trends.

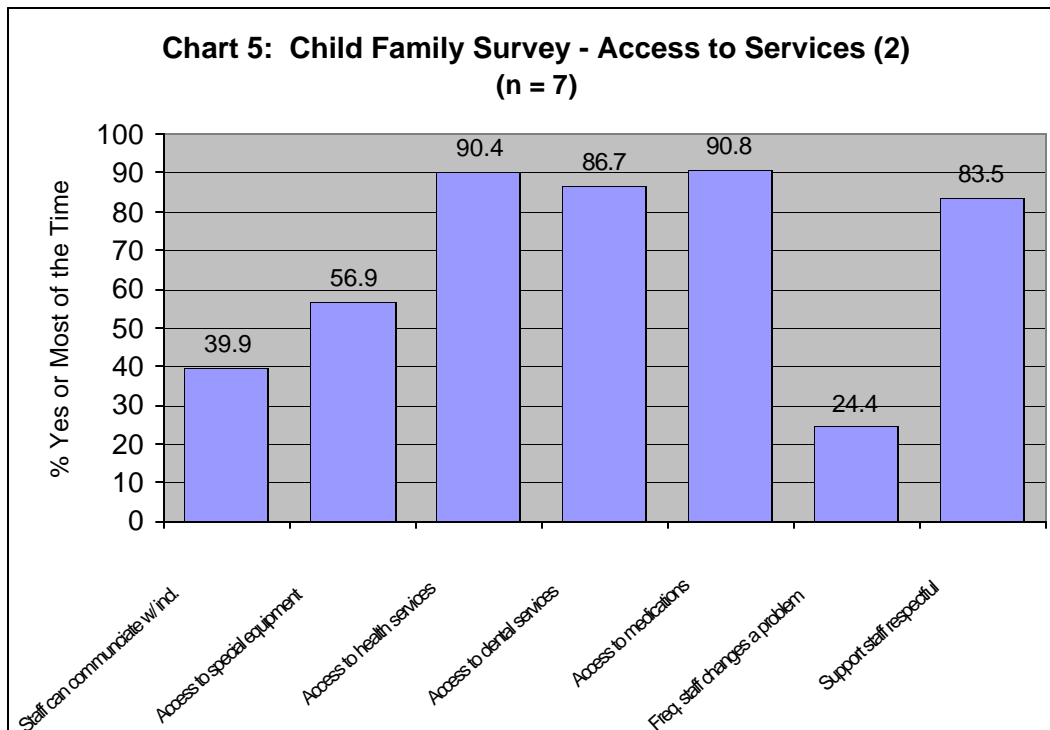
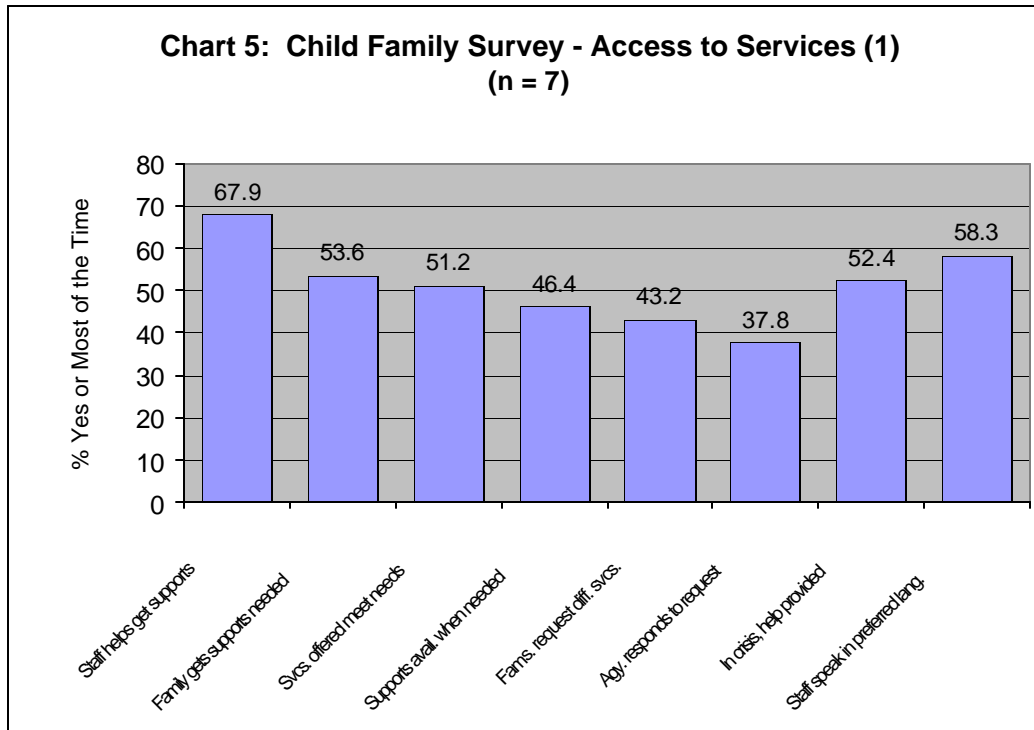


Table 18
Trends in Responses Above & Below State Average
Access to Services & Supports

State	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Q27	Q28	Net Sum
AZ							↓↓									-2
CA-RCOC	↓↓		↓			↓			↑↑		↓		↓	↓↓	↓↓	-8
MA	↓↓	↓↓	↓↓	↓↓					↓	↓						-10
SC		↑	↑	↑		↑	↑	↑↑	↑↑					↑		10
SD	↑↑	↑↑	↑↑	↑↑		↑↑	↑↑	↓	↓↓	↑↑	↑		↑	↑↑	↑↑	17
WA		↓↓	↓↓	↓↓		↓↓	↓↓		↓↓	↓↓						-14
WY	↑↑		↑			↓		↓	↓	↑						1

Choice and Control

- ♦ In this category, every state scored either considerably above or below the state average, indicating that there was very little middle ground when it came to choice and control. In Massachusetts, Washington and Wyoming, responses to choice and control questions were generally above the overall state average. In Arizona, Orange County, California, South Carolina and South Dakota, results were generally below the state average.

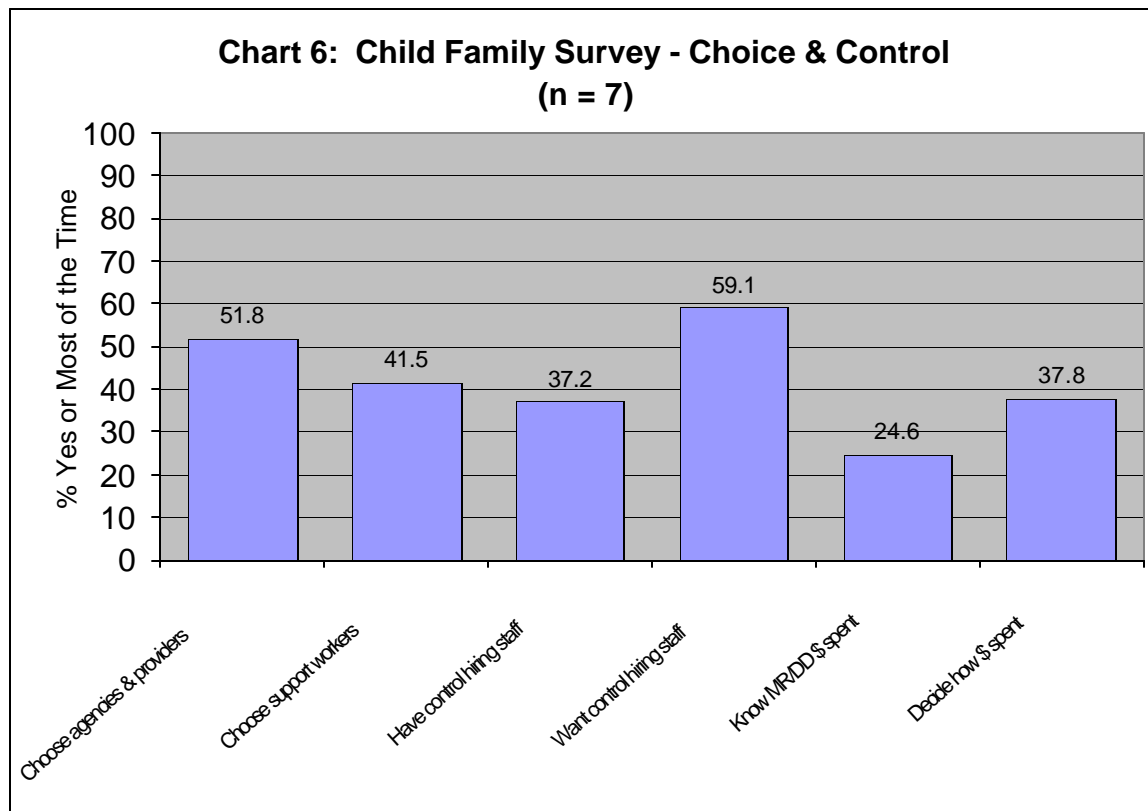


Table 19 Trends in Responses Above & Below State Average Choice & Control							
State	Q29	Q30	Q31	Q32	Q33	Q34	Net Sum
AZ	↓↓	↓	↓↓		↓↓	↓↓	-9
CA-RCOC	↓↓	↓↓	↓↓		↓↓	↓↓	-10
MA			↑	↑	↑	↑↑	5
SC		↑	↓	↓	↓↓	↓↓	-5
SD	↓↓	↓↓	↓↓	↓↓		↑↑	-6
WA	↑		↑↑	↑	↑		5
WY	↑↑	↑↑	↑↑	↑↑	↑↑	↑↑	12

Community Connections

- ♦ In South Carolina, responses to community connections questions were generally above the overall state average. In Massachusetts and Washington, results were generally below the state average.

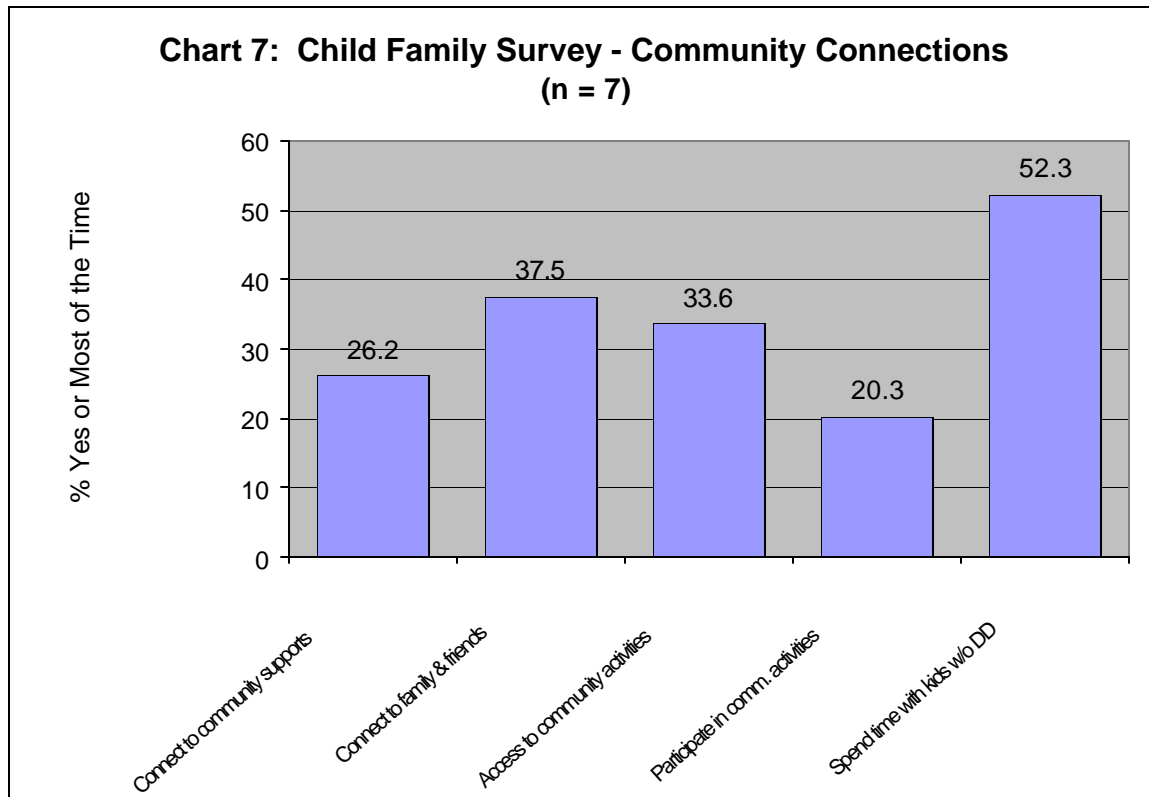


Table 20 Trends in Responses Above & Below State Average Community Connections						
State	Q35	Q36	Q37	Q38	Q39	Net Sum
AZ		↓↓	↑		↑↑	1
CA-RCOC		↓				-1
MA	↓	↓↓	↓↓		↓↓	-7
SC	↑	↑↑	↑↑			5
SD		↑↑				2
WA	↓	↓	↓			-3
WY						0

Satisfactions with Services and Supports & Outcomes for Families

- ♦ In South Dakota, responses to satisfaction with services and outcomes for families questions were generally above the overall state average. In Orange County, California, Massachusetts and Washington, results were generally below the state average.

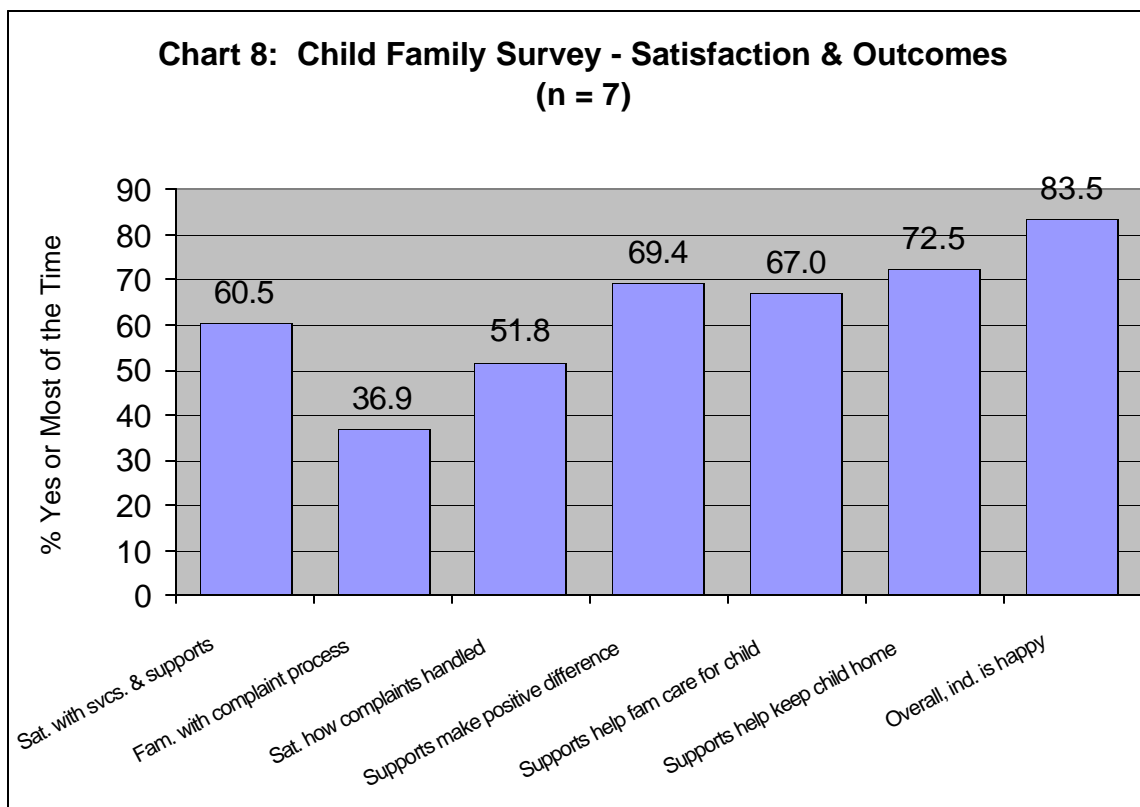


Table 21 Trends in Responses Above & Below State Average Satisfaction & Outcomes								
State	Q40	Q41	Q42	Q43	Q44	Q45	Q46	Net Sum
AZ		↑						1
CA-RCOC				↓	↓	↓	↓	-4
MA	↓↓	↓		↓↓	↓↓	↓↓		-9
SC	↑	↓				↑		1
SD	↑↑	↑	↑↑	↑↑	↑↑	↑↑		11
WA	↓↓	↓↓	↓					-5
WY	↑	↑				↑		3

Overall State Trends

- ♦ Looking at results across all categories, South Dakota and Wyoming had results that were generally above the overall state average. In Orange County, California, Massachusetts and Washington, results were generally below the overall state average.

Table 22 Overall Trends in Responses Above & Below State Average	
State	Total Sum
AZ	-6
CA-RCOC	-28
MA	-33
SC	18
SD	42
WA	-37
WY	24

Analysis of Open-Ended Comments

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. QSR NUD*IST (v.6) was utilized to code and sort the qualitative comments by theme. Themes included service coordination, staff, funding and budget cuts, education and training, health services and equipment, transportation, recreational activities, communication, transition issues, and overall satisfaction with services. The results of this analysis are presented by state below. Note the some qualitative comments from South Carolina were incomplete – specifically, comments were cut off due to the nature of their database.

The analysis of qualitative comments varied substantially by the number of responses from each state. In states where the sample size was large, such as Washington, a clearer understanding of the data begins to emerge. Regardless of the number of responses, these comments provide insight and supplement the quantitative results presented earlier.

ARIZONA

Approximately 35% of survey respondents from Arizona wrote qualitative comments. These comments are summarized by theme below. Respondents most frequently mentioned case management issues, followed by dissatisfaction with services, satisfaction with services, and communication issues.

Support Coordinators

Approximately the same number of respondents mentioned that they were satisfied with support coordinator or case management services as those who mentioned that they were dissatisfied. Respondents who were satisfied used the following words to describe their coordinators: helpful, informative, attendant, positive, thorough, professional, kind, knowledgeable, goes beyond his/her responsibilities, and efficient.

“So far I've had a lot of success with my support coordinators, one was most helpful, very informative, attended to my every request, question and response time always timely. She was always very positive which helps me stay happy and confident.”

“Our DDD support coordinator is [name]. We have never had a better more thorough, professional person handle our son's needs before.”

“We love our support coordinator. She is always kind and thorough. We appreciate the services we receive for our son. His life is fuller because of the services DDD has provided - we would have been unable, financially, to enrich his life through therapies, equipment, etc. on our own.”

“I'm very satisfied with all services offered to my child and everything you do for him. Especially [support coordinator's name] who has been conscious of the status level of benefit services for my child. She has helped me a lot when I have questions and need clarifications. She has always helped me.”

“My support coordinator (with emphasis on support) has been invaluable to C. and I. If I have questions, she answers them or finds the answers. If I have a problem of some

kind she does her best to help me resolve it some way. She goes above and beyond her responsibilities. We cannot praise her enough or thank her enough. She is the best!"

"The case worker my children has with DDD is excellent, she provides the necessary items and information I need and is very efficient."

"I would gladly like to say I'm very happy with the caseworker. She has been a blessing to me and my family. She is always there when my family needs her. She's a very good person. She's the person I call on to when I'm in time of need and don't know where else to turn, I call her."

Some respondents reported that they were dissatisfied with their support coordinator or case manager. Common problems included: lack of communication, turnover, and uninformative.

"My child is over 3 yrs. old now. But, while we were in the system we had 4 plus service coordinators which didn't enable us to get comfortable with one. That should be improved. Because of so much switching around my child did not get all of the therapies."

"What is the case manager supposed to do? I have to ask case manager to put in referrals for PT/OT/ST etc. But, when there is something I do not know and ask for help, the case manager does not attempt to help. For example: my child is in diapers. I asked the case manager to please ask around (other case managers, etc) to find out where I could obtain these very expensive diapers at the best cost. I was told to go look on e-bay! This case manager never even attempted to find out for me."

"So far in 6 years my son has had four support coordinators through DDD. The first one only for a couple of months, the second one until he was 3 years old. With the exception of the second one they have all been very good at providing what we need. However, all the services we have gotten so far has been because we have specifically asked for them the service coordinator have not ever volunteered the services that were available to us."

"I'm not completely satisfied with our DDD case worker though. She does not give me knowledge of programs, support or community service available. It seem like I hear about something, then I ask her and I don't seem to get useful information. It could be that our income excludes us from the activities, but I need to understand those limitations."

"Support Coordinator does not help in issues that concern my child's development, learning in school; and doesn't seem too concerned on any follow up issues I have regarding what social activities and family support is out there."

"It is unfortunate that you can't offer adequate pay to get adequate people. We have had four different case workers this year."

Overall Dissatisfaction with Services and Lack of Services

Several respondents reported that they are dissatisfied with services or need more services.

"I have been trying to get a speech therapist for my child for almost a year!"

"The biggest complaint we have is that we haven't been able to get all the services we need. One primary example is that my child has been evaluated as requiring two hours of speech therapy per week but DDD is only willing to pay for 1 hr. Also we have been on a waiting list for music therapy for two years - haven't received it yet."

"My biggest problem is the amount of time it takes to get services for my daughter. She had to wait almost a year, and then the amount of interviews I had to go through. This system needs to be simplified, and quicker."

"I think my child needs speech therapy and OT at home as well as at school. We've have not had a speech therapist in 2 yrs I really think it would her more on he development but they always tell us they can't get anyone. When she had speech and OT she improved quite a bit but when they no longer can he sign language dropped and so did her speech even though we work with her it is not the same."

"I have one complaint is about people not sticking around long enough. The people who I am talking about is therapy people my son is always on a waiting list. You don't have enough therapy people. Like right now, he is on a waiting list for OT and speech. He spends more time on a waiting list, its un-real. I say to myself why even bother anymore."

"This is a bad time for you to send me this survey. I have fought for five years to get a ceiling lift. Yes five years. You tell me why a child had to suffer. We are still waiting for other equipment that was requested. Money, what money, we get turned down for SSI. But we still buy his meds because of our insurance. We have bought diapers and wipes for 15 years. Having someone in our home to watch our son after school and before school is hard to come by, but yet they will not pay mom to stay home."

"There should be better support for family member who have a disability child. For example, parent lose job, parent goes to DES. DES puts parent in job program. Job program don't work. DES gives up on parent."

Overall Satisfaction with Services

Overall Satisfaction with Services was a frequently mentioned topic.

"Thanks for the support!"

"I would like to thank you about everything you help me and my child."

"I think that this survey has been very helpful to me because I can value the services that my son receives and it helps me to be grateful for what we have. I think I would have lost my mind if it weren't for this agency and all the support my husband and I have received. It has helped us to accept and love our son with his disabilities and it has

made us better people with a goal and that goal is to help him and teach him and lots of patience.”

“Thank you for all the help you give my family when needed.”

Communication

Overall, respondents reported being dissatisfied with communication.

“I have yet to get her an evaluation (sensory) completed. It has been over two months now and time is running out. I do not have access to a current respite care providers list, the list of names I was given is very out-dated so I still need a current list. Every appointment is forever in getting someone to call me and set it up with them. I have not been very happy with a lot of talk and no action.”

“Are you going to mail out something that gives us all this information you think we all need to know? It would be great information to have.”

“No one has ever told me how much my daughter gets money wise, and how we can spend. I have asked for a list of music therapist and have not received one yet. I don't know what other services are out there for my child. Please send information.”

“These services that are necessary and available are not known to a large population. I have no solution for this problem, but I have seen children not receive any services until they reach school and so much time is lost at that age.”

“I would like to know about the other services/therapies, etc. offered to my daughter.”

“There need to be more Spanish speaking support staff available. My support coordinator needs to communicate more often with my family and my child.”

“What we really need is some kind of service that can coordinate care (medical, mental, educational and therapeutic) between doctors, mental health services, DDD, schools and therapists. It is absolutely overwhelming trying to work singly with each area and they try to coordinate plus take of my child.”

Staff

A few respondents mentioned staff issues.

“I really appreciate the time and effort that the staff has for my child so she could learn how to speak. I thank them very much, them and everyone else my child has worked with now it is not hard for me to understand my child in what she needs or wants.”

“I thank all of the program staff for all they did for my grandson.”

“Changing help is a constant problem and just as you get a working knowing what they're doing, they are replaced with new people.”

Respite

A few respondents mentioned that they were dissatisfied with respite services.

“The quality of respite care providers is low and are difficult to obtain.”

“My family was denied extra respite hours - not for my DD child but for my older DES children. The respite hours were used primarily to take my DD child to doctor appointments and to do errand running to support my family. DES adoption subsidy denied my request for more respite saying I was using my respite hours as child care, which in a way, I was, but taking four DDD and three DES adopted/foster kids to the doctor or grocery store is no easy task.”

“Respite providers are really difficult to find/keep.”

Health Care

A couple respondents wrote comments about health care specifically noting the need for insurance coverage for alternative health care.

“I have been very disappointed in the lack of willingness on the part of DDD to help cover the cost of "alternative" health care for my son. For the past seven years I have paid out of pocket for cranial sacral therapy which has saved DDD tens of thousand of dollars in surgery cost that were recommended by the orthopedist at CRS. The 'alternative' care has benefited my son greatly physically, mentally, emotionally, as well as being cost effective.”

Education

A couple respondents noted that they were dissatisfied with their child's educational services.

“School District is not very supportive with needs, sometimes.”

“More tutoring services need to be made available - especially for older and higher functioning children. Services are limited in the school setting. DDD children need a lot of one to one instruction. There are services but not many providers in the our area.”

Recreational Activities

A lack of recreational activities was mentioned by a couple of respondents.

“They don't invite disabled children to the playground. There is no one to monitor or watch them.”

“Wish there were more places besides [provider] that use respite hours to take the child on special activities and sleepovers.”

MASSACHUSETTS

Approximately half of survey respondents from Massachusetts wrote qualitative comments. These comments are summarized by theme below. The most frequently mentioned issues were problems with communication followed by dissatisfaction with recreational programs or services, a lack of services or eligibility concerns, and overall dissatisfaction with services.

Communication

Communication issues were the most frequently cited problem. In particular, respondents noted difficulty getting sufficient and timely information, needing information on particular services or supports, and poor communication. One respondent mentioned language barriers as a problem.

"I don't really know how much I can use of the services out there. I did get help when I asked for it and it was prompt, but I don't really have a clear understanding of what there is that we could take advantage of."

"For getting information on services, I find parent to parent communication the key to finding out things. For instance, just registering your child with DMR, a parent told me to do this, not a professional. Hospital staff at birth were not knowledgeable about what to do when you have a child with Down syndrome. They just said 'oh you'll get help' and that was the end of it. If I hadn't met another person who had a child with Downs I would not have known about DMR. The same with early intervention, this was from another parent who helped get us started. EVEN today there are many services out there our family still doesn't know about or how to tap into them. Much more communication needs to be addressed. I have called the DMR office several time for help – I have always left messages and no one returns calls. Unfortunately when people do need help, sometimes it hard to find it."

"Sometimes I think agencies need to let parents know what services are out there because we may not know what services are available. It's hard to get what you need for your child if you don't have information about services."

"At this time, we do not feel educated on the support options open/available to us now or in the future."

"My biggest concern is I don't know what else is available to me. I would love to be informed about staying in the loop and learning what else is available."

"DMR staff are not well coordinated. If you search you can find services and sometimes get access to them. However, these services should be proactively offered to all families and families should be updated periodically."

"I don't have a clear sense of what DMR can do for us – and it sometimes feels like DMR would prefer to write a \$200 check than enter into a relationship with us. It would be a lot more valuable to us if we could readily know what possibilities are available to us through DMR so we could plan better."

"We have no written communication whatsoever, with no sense of benefits. The agency is a tremendous disappointment. What a waste of our money."

“Whenever I have called DMR they have given me the runaround. No help at all! If you help please let me know—I’ve been given numbers for other agencies but NO help from DMR!”

“I never have received any support or communication from DMR in 99 years. If I need information I have to search for it myself.”

“We have gotten very little support from DMR; we rarely get any information from them (like updates, etc. in the mail). I am not even sure anymore as to what services we are eligible. We could use additional family support but don’t know if the DMR could help us. I would greatly appreciate at least finding out who my case manager is and what he/she can do for my family.”

“It would be nice to receive some type of newsletter from DMR about any activities, seminars, etc. that would apply to people/kids with disabilities.”

“My wife speaks Japanese as her primary language and has difficulty with official documents. Translation services have been inadequate. I, too, have found many of the forms we get to be vague. We didn’t even know we had a service plan.”

Recreation and Community Inclusion

Many respondents reported that they are dissatisfied with recreational activities available to their children and the lack of inclusion in the community. One respondent noted how their flexible funding is used to pay for recreation, while other respondents noted insufficiencies in recreational activities, especially during the summer. In addition, respondents mentioned the importance of social skills and friendships for their children with disabilities.

“...we do rely on, and greatly appreciate, is the flexible funding program coordinated by program coordinator which allows us to use this money for S.’s adaptive skiing and his camping during the summer. He certainly has more opportunities than many, however, all these activities are very expensive – even for a middle class family.”

“Where I feel I could use more support is with recreational activities on weekends. Also, I was surprised to find so little inclusion support in Massachusetts. I moved from [city] five years ago where my daughter was included in regular camp and recreation activities.”

“M. is not educated in his hometown school – because they do not have a program. He attends a life skills pre voc program. He is therefore cut off from any inclusive social school activities that his normal peers enjoy.”

“More summer camps for children with severe disabilities that are affordable for low income families would be nice.”

“The only extracurricular activities I have seen “available” are activities that do not seem to be ‘possible’ for us. My son is autistic and basketball and soccer and team sports in general are of no interest to us. It’s like pushing uphill and it’s not fun. I would love services to be geared more to the individual, i.e. cooking, crafts, music. I think we’ve all heard how beneficial music therapy is. Why is it so difficult to find a program?”

Inclusion in the community was mentioned by several respondents. In particular, families mention that they had difficulty including their child in community activities.

“Community access is very difficult.”

“My child is not a part of the community we live in anyway, although I have expressed this desire to DMR staff for years. Community connections are very lacking for my child. We receive no support with this. My child has not one child in his life as a peer or friend.”

“We live in [city] and we feel very isolated here. There are many recreational activities in the city, however, there is nothing in our area that a 5 year old in a wheelchair can do. J. has also been a victim of discrimination and I have found no way to pursue this issue legally. She has been sent the message that she is not accepted in a lot of places because she cannot walk. This upsets me, however, we have no avenue to change this. Transportation and accessibility are very difficult and not financially in our reach. J.’s free to move around in her power chair at home but when we go out we cannot bring her mode of mobility. Raising a disabled child is economically and emotionally draining. I find it very difficult and often worry about the things her sister sacrifices to allow J. to live at home.”

“Also, community education is nonexistent with disabilities to be part of the community. This further isolates the family. Without DMR, or other state supports for children and adults with disabilities, the productivity of entire families can be lost which negatively impacts the community and the family.”

Lack of Services or Eligibility Concerns

Respondents frequently mentioned a lack of services and restrictive eligibility criteria as a concern. Specifically, families mentioned needing services like OT, PT and Speech, or supports in general. Other families mentioned not being able to access services due to their income level.

“Our son is in need of OT services. Our insurance does not cover this and it is not clear to us whether there is some way to get OT for him which will be paid for somehow.”

“We could never get any in house supports or any help at all with community involvement and all these things – lack of supports and my child’s disability is what led to her placement in residential. There is not enough available to families for support. And this sad and terrible situation is very upsetting to families!!”

“As parents we feel it is extremely important that services and funds be available to allow us to maintain caring for our child in our home. The goal is to provide as much support within a loving, nurturing and caring environment that encourages as much independence as possible enabling our child to experience life to its fullest despite numerous impairments.”

“Our DMR provider is excellent but funds and services are just not available. I have two special needs children and I would like to know of any support I can get on caring for them. I am unable to work because I can’t afford to pay a reliable caregiver for my boys.”

“We have been on the waiting list for respite now for five years. No services available. This would be an incredible support for us. My husband and I are simply drained. We

have a seven-year-old daughter with C.P. Both of our families are not close available to help out. The stress of caring for our daughter has resulted in a great strain on our marriage and our health.”

“I would like to see more parent support groups, I'm not sure if this is in my area or not. I am a recently divorced parent with a son with PDD-NOS it would be helpful to have a group like that or better yet, how would I start a support group.”

”I haven’t received any help from DMR for two years. Not that I didn’t need it. I’ve tried for SSI for my son, but was refused. We made too much money. (That was five years ago). I would like help from DMR but they say they don’t have enough funds. Difficulties continue due to limited out of home respite. We need out of home respite and nursing care for R. to continue to live at home.”

“We are not eligible to receive SSI. We are required to pay \$212/month for Common Health. We are financially strapped. Unless I divorce my husband or give up my child's custody, we will continue to be financially strapped. Middle class families are left out!”

Overall Dissatisfaction with Services or Agencies

Overall dissatisfaction with services or agencies was one of the most frequently cited issues.

“Although my child is ‘registered’ at DMR and she is severely cognitively and physically disabled, we have not received any support other than a brief, unmeaningful interaction with our service provider. I was told there were ‘no funds’ available for anything. I’m not sure what benefit it is to my daughter to be associated with this agency?”

“We have not gotten much support or a “family service plan”. SSI does not apply because of our income level. We only receive occasional funding for special programs. It would be nice to see a more proactive approach to DMR family support or annual meetings to check and see how the needs are changing/challenges.”

“Sometimes promises of help never materialize. We feel very much alone in dealing with our child’s health concerns, recreation, future, planning and other challenges. Perhaps because we fall in a fairly high-income bracket we are out of the loop. I am a single parent of a special needs child and two younger children. The only help I have is a respite worker and 30 overnights at the respite house. In the beginning it was 36 overnights. They keep cutting the time, the 20 hour a month respite worker I haven’t even been getting someone for all of them. They are not helping me get anything but high blood pressure. My health is not the greatest. They could care less. Other people are treated better, some are not. Some get more help who need it less than me or my daughter. And who are less handicapped. Everyone should get the same fair treatment. I can’t believe how I get the runaround from everyone.”

“I have had a very poor experience with this agency. I did receive a stipend (\$300 - \$400) annually which helped me send my son to camp. But, I have received no advice or support from any staff or worker. Usually, they said that there was no money or staff to help. I have only spoken with a worker by phone – never in person. I would love some support – but I have basically given up any hope of assistance from DMR. “

"The DMR, when we contacted them several years ago about our son, made it very clear that no funds were available to help our child. That applying for services was an arduous process often met with rejection or a one-time-only stipend. Our child receives the attention he needs through a special school outplacement we fought for with a lawyer despite the objection of our city, and we provide for him personally with our own money to fund his needs for equipment, services, etc. We personally hired a private tutor to work with him, and we work with him ourselves on PT and OT issues. The DMR has never done anything to be supportive, discouraged us from even applying and made everything as difficult as possible. I did apply for funds at the beginning, and one time received \$350 for respite for one year. The amount of effort required for that one small check was definitely not worth my time and energy."

Overall Satisfaction with Services or Agency

Overall satisfaction with services or agency was frequently mentioned by respondents.

"I feel that your services have helped a great deal with my son."

"We are very grateful for the DMR services we have received which include respite, stipends for parent conferences, and information on therapy and recreation and health organizations that provide programming and offer some subsidization. It makes a big difference in our lives."

"The DMR and Family Support Services have GREATLY helped my family. I have a unique situation. My son who is 4 yrs old is disabled. I also have children seven, ten and nineteen. I have been suffering from advanced osteoarthritis for the past several years. It had gotten to the point where I could hardly walk because my right hip was bone on bone. I could no longer pick up my son or bathe him or do any therapy with him. The DMR helped me place my son in a wonderful respite home for 11 days so I could go to the hospital and receive a total hip replacement. The DMR also gave my family financial aid to help us pay for in home respite care while I am recuperating. I could have never had this surgery if it had not been for the help and support of the DMR. Hopefully, I will have a full recuperation and be able to care for my son at home for many years."

"Family Support, DMR has made a big difference in my son's life. I don't know what I would do without them. By helping my son you help me too. I am satisfied with all your services. Thank you, you are the best."

"I can not express how grateful I am for the money I receive through the flexible spending plan. I am a single mom and absolutely believe that through devotion of my son he will succeed. In order to do this I need the ability to provide activities and programs to aide in his development. With the flexible spending I am able to do this. My son is a ray of sunshine. He is a happy and smart boy. Anything I receive that helps me to improve and expand his abilities is a God send."

Respite

Respite was mentioned by several respondents. Most respondents noted that they were dissatisfied with respite services usually due to a lack of providers, lack of funds, or that the providers are inadequately trained.

“Without respite or campership funds, I don’t know what my son would do. These services are needed and hopefully they won’t get cut anymore than they all ready did!”

“We did qualify but have never received respite. We have received a stipend when I called inquiring about the Respite availability. This has happened twice I believe. Our son is fairly high functioning, but does require constant attention – more money for respite would be a great benefit. We have dramatically changed our lifestyle to accommodate our son’s disability – while my taxable income is high, that because we are liquidating retirement assets to enable both my husband and I to work part-time in home-based businesses. Our income this year will likely be less than \$20K –we could really use more respite care!”

“I use the Flexible Spending Plan to get cash benefits that I use to pay providers a salary that makes it worth it to them to provide respite.

“My daughter would be happy going to a respite if she could have the same people working there. She seems a lot better coming home from there when there are people her own race. Sometimes she is worse when going overnight when there are only Spanish speaking people watching over her that don’t speak English and/or have no communication speaking people with sign languages experience. She will give me a hard time for a few days afterwards and seems to be in a mania state for quite some time.”

“I also wish that DMR or other agencies could help families in identifying/training respite workers. [Hospital] had a program – wonderful for this – called Project Respite Care. Unfortunately, it has been discontinued because foundation funding expired. It was a wonderful concept because it provided in-depth training to students who had the potential for becoming involved as professionals in related health professions - while providing respite to families. Families have a very tough time finding trained, quality respite workers.”

“It is our opinion that the number one challenge for the new century, decade, year, or however you want to classify it is to create homes where parents can bring their children when they need a break. These need to be quality respite homes with flexibility to accommodate varying lifestyles. This will allow parents the ability to patch holes in their school gaps and to allow them to return to work or do things that otherwise wouldn’t be possible.”

“Hiring and retaining respite workers has been difficult.”

“It is difficult to find caregivers to provide respite care for my severely impaired child, and the allocation only pays for 40 hours a year (if I use it only for respite, not for any other needs). I get info about programs on vacation days and weekends which sounds great but are not something my severely handicapped child can participate in. Respite care is by far my most urgent need. I am exhausted and seldom get a break.”

Funding and Budget Cuts

Funding and budget cuts were another frequently reported concern.

“At this time my son and our family do not receive any support through the DMR. Previously, we received a very small amount of money for flexible funding, but due to budget constraints and a change in requirements, we no longer receive the flexible funding.”

“Due to the budget crisis, services are being cut for our vulnerable children. It is a big mistake to cut this services. Children with disabilities need all the support they require in order to have a better future.”

“DOE/DMR grant dollars are hard to come by. Long waiting list. Can take year or more to get funding for home services/flexible funding. It is very expensive to care for an autistic child with many needs. I have only been receiving about \$600 per year – which was just cut this year to about \$500/year. The support people are great – funding is hard to come by.”

“Personally I don’t think our governor should take any more services away from these kids. If it wasn’t for a respite house, my husband and I would never have a babysitter as my family doesn’t volunteer. Does anyone really know what its like never to have relief? I have had to schedule surgeries around school hours so I could immediately come home and take care of him. If it wasn’t for the dedicated caregivers myself included, [public official] would have huge state bills for institutions!”

Health Care – Equipment

Several respondents made references to health care issues such as needing equipment, difficulties paying for insurance, and the need for accessible and quality dental care.

“I have two girls who were recently denied wheelchairs. Process started in September. We are going for an appeal 5/19 and girls have not been able to be taken many places because they cannot walk far. It would be helpful to acquire a list of things (information) we need so that prior approval would go more smoothly. The professionals working with the girls don’t seem to know everything needed and often MA Health people are not very helpful.”

“My child has severe developmental delays. She doesn’t receive any public benefits (such as SSI) because we are over income. I don’t think my child should do without, because her parents work. A disability is a disability, whether your poor or middle class. I pay almost \$300 a month for an HMO and I pay over \$100 for healthcare for my daughter. She should at least be entitled to free healthcare.”

“I would appreciate any information about dentists in the area of Worcester who takes Medicaid and who take care of autistic children. We’ve been turned down by dentists when they found out she was autistic (my daughter). Thank you very much.”

Education and Training

Most respondents who mentioned education and training issues were dissatisfied with current programs or services. In particular, respondents talked about overworked staff, cuts in services or difficulty accessing services, overbearing paperwork requirements, and inclusion in mainstream classrooms.

“More than half his success is directly due to the school’s staff-teachers, aides, consultants – and to his peers who give generously – and receive a great deal in return. If you want to see how things can work really well, contact me, visit his school and meet my child.”

“It can be very difficult dealing with the school system due to budget cuts, services or consultations are very difficult to obtain.”

“How can DMR help get appropriate educational placement? Children are not supposed to fit into a school system’s program(s). The school systems are to help the children with what they need.”

“Attending to the needs of the children takes precedence over paperwork, yet paperwork takes 50% of every day they are at school (i.e., 3 hours per day).”

“I find that attempting to integrate my child (actually both these w/a disability) into inclusion classes has been very difficult. Although I am frequently told that neither child is disruptive in class, the resistance toward inclusion is tremendous. There are strong barriers that need to be removed in education. I also find it difficult to socially include my children because schools are not at liberty to distribute names of children who may be potential playmates and my children have a difficult time distinguishing potential ‘friendships’ from just ‘classmates’.

Caseworkers

Satisfaction with caseworkers was mentioned by several respondents. Approximately the same number of respondents noted that they were happy with their caseworkers as those who reported that they were dissatisfied. Those who were happy noted that their workers were kind, courteous, respectful, and always available.

“Overall, very happy with DMR worker. She has helped us get a ramp for our house. She’s always kind and courteous.”

“We have received nothing but wonderful service from our worker and her staff. The money that has been provided has allowed us to purchase things for our daughter to make her life a lot happier and easier. As well, when she was hospitalized for a lengthy period a couple of years ago, the worker got us an emergency advance on some of our funds to pay for meals, commuting to Boston, etc. It was invaluable and her kindness will not be forgotten.”

“Without the support of DMR and our case manager I don’t think we would be in the position we are in with our son and daughter, who is in a residential setting at [city]. We are thankful for our case manager and the services DMR has to offer.”

For those who were dissatisfied, issues included: poor communication, high turnover, and large caseloads.

“Please have the DMR workers, come to see the families they work with. I haven’t seen my worker for about two to two and a half years. At least a call to see how we are doing. I guess it makes us feel like we don’t matter if we don’t hear from you.”

“We have had many different case workers, the change is frequent. Nobody contacts us, except by mail if the personnel is changed.”

“We have a caseworker, who is helpful when we contact her, but she has a huge caseload and we get lost in the files unless we are very specific about what we want. We don’t know what services are available to us.”

Family Support

Several respondents mentioned that family support was very helpful to them, particularly the flexible funds.

“My husband and I choose to use our son’s allocation to help pay for an annual family vacation. This vacation is a big treat for our family. Without the help from this, we would not be able to afford a yearly family vacation.”

“Family Support, DMR has made a big difference in my son’s life. I don’t know what I would do with them. By helping my son you help me too. I am satisfied with all your services.”

“The family support program (financial reimbursement) is the only program we currently participate in. It is appreciated and helpful.”

Staff

A few respondents commented on staff issues. Slightly more respondents indicated that they were dissatisfied with staff.

“The supports that I receive – mostly personal care assistants – make a huge difference in my life and my daughter’s life. I’m not sure I would be able to work without these supports.”

“The main problem we have in order to keep our daughter at home is finding the right people for the right hours to assist. The care coordinator has tried to help find people, but this is still the most difficult aspect.”

“Biggest problem we have is staff turnover. With an autistic child this is difficult. Just as he is getting into a routine, a therapist may leave due to many reasons (burnt out, needs more money or wants to work less hours). It takes months to find replacements.”

“Pay scales and for in-home support staff is quite low for our area, making it difficult to find, train and keep appropriate staff, especially given the high level of needs of our children”

Transition Issues

A few respondents wrote comments regarding transition.

“My concern is once my son graduates what will he do and what services will be available so that he can become a ‘working’ part of our community and not receiving an SSI check. My concern is for young adulthood and making sure that he is proud of where he is at in life and what are his choices for work. My concern is independence and job future. My concern is for the next stepping stone of life, social awareness, safety, growth, belonging, pride in his work and life, being a homeowner, a job that he enjoys, the transition from childhood to adulthood, when services start to disappear.”

“I also wish that the DMR could begin working with families to help plan how to care for our children after they are 22. It is very stressful to have to wait until the teen years before we can begin to plan for such a huge problem area. In this area of West County there are many young people with significant handicaps approaching that transition age with no clear guidelines.”

SOUTH CAROLINA

Approximately 8% of survey respondents from South Carolina wrote qualitative comments. Due to the relatively small number of comments, all comments are shown by theme below.

Case Management

Case management services were mentioned by a couple of respondents.

“My major concern is just not knowing what my child is eligible for if anything. Every time we are up for review we have a new caseworker. I’m not sure as to why this happens.”

“J. was started with [provider] at two years old within the first year he had four case workers. So he never got close to anyone.”

Home

One respondent mentioned that they were still waiting for modifications to their home.

“Items listed in original plan two years ago are still not in effect, wheelchair ramp, appropriate bathing and facilities, addressing child’s needs etc.”

Health Care

One respondent noted that they have difficulties regarding insurance.

“I am having a very hard time with the board of disabilities in paying bills not covered by my insurance.”

Education and Training

One respondent mentioned that she is dissatisfied with educational services.

“I don’t feel like my son is getting the proper training that he needs in school that he is going to need to live in life. I think he’s fallen in the crack of society and his school. I wish there is more that can be done to help him succeed in life.”

Communication

One respondent reported that he is dissatisfied with communication.

“I would like to know why S. is not eligible for SSI. When he is considered disabled and if these benefits are available to him. How do I go about getting it for him? My major concern is just not knowing what my child is eligible for if anything.”

Overall Satisfaction with Services

A couple of respondents noted that they were satisfied with services.

“We are so pleased with the outcome of the program. My daughter first began receiving treatment in March of this year. She showed improvement right away. All of the services were covered by [provider].”

“Thanks [provider], for being concerned about the child or children being placed in these homes. I personally think every agency that helped me with the adoption of my little girl. I couldn’t do it by myself, everybody helped when I called.”

SOUTH DAKOTA

Approximately half of survey respondents from South Dakota wrote qualitative comments. These comments are summarized by theme below. Respondents most frequently mentioned family support services, followed by case management, and overall satisfaction with services.

Family Support

Almost half of all respondents mentioned family support services. Most respondents who mentioned this topic were satisfied with services. In particular, respondents noted that family support services helped their family member to live at home, and satisfaction with support coordinators.

“We are very pleased with the services we have received. Without all the help and support we have received, I don’t think I could have survived. We have attended a lot of wonderful educational conferences that have helped so much—without the funding we received to pay for these it would not have been possible for us to attend. Our family support person is a remarkable person. S/he does a fantastic job with all the families s/he works with. It doesn’t make your problems go away, but s/he makes life a lot more bearable.”

“I feel the family support program in [city] is wonderful. She is a great person to work with. She is very smart and knows a lot. I think she does such a great job; s/he has always been there for our family. She is a wonderful person!”

“Family support’s program has been just awesome! It has been a real big help with our son. We have a great coordinator; she does a really wonderful job.”

“Family support program has been wonderful. Please continue to support or increase the support of funding for this program. Our family would not be able to do what we do for both children without the help we have received.”

“Without the assistance of family support services, it would be extraordinarily difficult to provide our daughter with the services she requires. Staying home to take care of our daughter has put significant financial strain on our family, so we are exceptionally grateful to family support services for everything they supply us with. Our service coordinator does a tremendous job, and s/he is very supportive and friendly.”

“We are fairly new to family support but are enjoying having it so far. Our coordinator has been very good for us. She knows a lot of things as far as our rights and the rules that we don’t. Can’t wait to have my coordinator sit in on an IEP—as I really need support for that.”

“Family support has helped us keep our child in our home where he belongs.”

“Family support is wonderful, we are very grateful for all services we have been provided the past few years. Most beneficial is the medical waiver.”

“Family support has been a big help. The diaper and wipes were expensive for us. Respite care makes me feel good that I can give the caretaker which is usually family

members something for helping with our daughter. If it was our money they would never accept.”

“The family support program has helped us care for our child at home. Without that support, I am not sure that it would be possible for us to care for our child at home.”

Other respondents were concerned about cuts to family support, eligibility problems, or lack of family support services.

“It is my understanding that family support no longer helps with vehicle or household bills. This will make paying all our bills very difficult. We have an old house and two awfully old vehicles. My husband works two jobs and will probably have to have me begin work – daycare is impossible for us, no one wants her – wheelchair, feeding tube, etc. If I do find daycare she won’t get to summer programs (therapy, school, so on.) I feel that we are now in an awful bind. But I know nothing will be done to help us. Just like all programs, we never get the help we need; it is always dumped on us. We live on five to six hours of sleep by the time we meet all her needs, and my husband works his 70 hours a week. We’re exhausted. Family support used to be there for us, but no more. Is there a program that pays daycare while I work?”

“I know funds have been cut, but the hardest part is vehicle and home repair expenses. This program helped us a lot in the past few years.”

“I only wish that family support got more funding for people who need it in times when things are tight. They should not do any cut backs on funding of money, we need this sometimes. Otherwise, family support is a wonderful service to have.”

“[Name] is a great coordinator. S/he is limited by budget constraints as to how much help my daughter can receive. The funding for this program is horrible--\$500 is not sufficient, considering the outrageous \$250 it costs us every weekend to get care for my daughter. She is great about funneling the money when it is available, but there is just not enough available.”

Case Management

Satisfaction with case management services was a frequently mentioned issue. Respondents used the following words to describe case managers: kind, go the extra mile, there for the whole family, empathetic, considerate, willing to listen, helpful, responsive, easy to work with, caring, kind, accommodating, and empathetic.

“Since the service coordinator has come into me and my son’s life, things are immensely better. S/he always calls to see if I need anything if s/he hasn’t heard from me. S/he is caring and kind and has found programs for my son.”

“First my service coordinator has been great. We had two before them that were good, but s/he has really gone that extra mile for our family. I feel like s/he is not just there for my son, but our whole family.”

“[Service coordinator] is very empathetic and considerate of our needs. It is very difficult to ask for help and she helps make it easier. S/he is very in touch with my feelings and willing to listen to me when I need to talk.”

"Our coordinator is very helpful and a joy to work with, without him/her I wouldn't know where to turn to if a need came about. S/he may not personally be able to help all the time, but s/he's right there with the answer to who can help, and s/he always checks back to see that our child's need has been met. We can't thank him/her enough for all s/he does for us each and every day. Peace of mind, that's what we have!"

"[Name] has been an excellent family caseworker for my family. S/he has made many difficult situations very manageable and we appreciate him/her being there for us and all the support s/he gives us. We have not had to experience a change in caseworkers but I would imagine that would make things difficult as we have spent quite a bit of time building a relationship. This was on my part and I appreciate her persistence in the interest of my child."

"I think that s/he is doing a great job. S/he has made a difference in our child's life!"

"[Name of case manager] is an angel, a tremendous help, and a friend, without a doubt. Without him/her, my son would not still be living at home."

Overall Satisfaction with Services

Several respondents indicated that they were satisfied with services.

"We are extremely grateful for all of your assistance. She has been very helpful and supportive. Thank you for all you have done."

"The services we receive have been really great! We didn't know anything was wrong with our son until five months old. We didn't know what to do next. Right away, we learned that there were a lot of services to help us with our child. Some therapists travel from out of town to help with him. We're grateful to all of them!"

"We would like to let you know how very grateful we are for everything we've received."

"This program has made our lives much more normal. My children are average—I love it. Having help and so much information has lessened the fears for all. We have become educated about disabilities and are learning to deal with what we need, yet be part of our community. We fit in, and to my other children, that means everything. We have learned skills to handle the disappointments. We are enjoying happy, meaningful lives. Many thanks, she has done so much and cared so much."

Communication

Communication was a frequently mentioned topic. Most respondents reported needing information about available services.

"I think that the staff should call the family more. Once every six months is not acceptable."

"That would be my biggest grievance – the federal government has these programs out there but doesn't want anyone to know about them!"

"Information is given to parents in the form of a veritable truckload of paperwork. In addition to being too much paper, it uses terms used by professionals, and is not generally understandable by average folks."

Home

A few respondents wrote comments about the home environment.

"Our support coordinator has been a godsend for us. I care for our disabled son at home and I do not know if we could have done that without him/her help. S/he is an angel and we have been very lucky to have him/her help us. S/he is always there when I need help with something."

"Our family is in desperate need of a new furnace for the house we live in. I was told I can get an A/C unit. We can live without A/C but a furnace for the winter would be more useful. Our kids' immune systems are very poor, so we will probably be living in the hospital this winter. All we are asking for is heat, not air, for our three special needs boys."

"Also would like to see medical insurance provided to single moms caring for 'special children' at home. Faced with the decision of putting their child in a home and being able to work to support a household or staying in a marriage only to make sure the child can stay at home is a miserable decision to have to make."

Education and Training

A few respondents reported that they are dissatisfied with education and training programs.

"My requests regarding our child's services have often fallen on deaf ears, met with resistance, or been completely denied at every turn. It is ridiculous how as a parent we have 'the right' to get the services our child needs, but cannot get the school system to agree to or provide these services. Compared with other school districts, our child is receiving the bare minimum and we had to fight to get that."

"Our child still attends public school. Her special education teacher for the last two years could have helped us a lot more with our child's education and goals. Next year, she will have a new teacher. Hopefully, it's all for the best. The family support program has helped us considerably. We are so lost when it comes to government programs. I feel the school needs to help keep the parents more informed. The government programs don't seem to want handicapped people to be well informed. Help!"

Transportation and Distance to Services

A couple respondents indicated that the distance to services is an area of concern.

"Really disappointed that car repair has been removed from our services. Receiving help with the simple maintenance of oil change which transpires from accumulated miles for therapies, doctor's appointments and surgeries."

"We would probably do things the same whether there was a family support coordinator or not. In South Dakota, the problem isn't how to pay for it, it's the distance to reach

things. Receiving services is not the problem, getting off work to drive to [city] is the hardship.”

“There does seem to be a limit in aid for rec. activities for children with disabilities (in our area, anyways.) There are so very few facilities or activities locally that we travel to [city] and scrape by funding-wise to participate in swimming and track.”

Transition Issues

Transition issues were mentioned by a couple of respondents.

“As my son gets older (he’s 18 now) I’m beginning to worry about his future. I’m not absolutely confident that the services that are provided in our community will suit his needs. Example: I’m told there’s a three year waiting period for a group living situation and that he can’t apply until he’s 21 – that will put him/us in a situation where he’ll be living at home until he’s 24-25. I don’t mind that, but will that really be the best for him?”

“I am concernedly wondering what will happen when she turns 21. Currently, placement outside the home at 21 does not seem appealing, and it feels like all the family has done to keep her in the home was in vain. I hope not. I wish she could continue with current services, have a day program, alternative to work for her, that would include standing table, PT, swimming, range of motion, massage therapy, activity program, outdoor activities, and a respite program.”

Respite

Several respondents mentioned respite services with most respondents dissatisfied with respite care.

“Respite care has been a godsend for us.”

“My child is two year old and is tube fed. She is just learning to sit up briefly. She cannot do anything for herself. She gets PT, OT, and ST, although she only makes sounds, not words. She has a v.p. shunt and is on several medications daily. She has a very strong gag and wretches often. It is hard to have her in public because for her to be happy she wants to lay down and not be held upright for long. She hates her car seat. So what this means is that I am home with her all the time. I need someone to come in regularly to give me a break. I have some help once in a while, but not on a regular basis. We have two older children ten and seven – they need me too. I’m stressed out. One day a week would be great. I need help.”

“It is hard for me to find someone to care for my son if I need to do errands, for even two to three hours. Where I live, they want paid up front. So I take him along and get really stressed out.”

“One of the greatest needs as a parent is, I feel, more qualified respite providers. It is hard, I feel, to find a mature babysitter who is willing to handle the needs my child presents.”

Funding and Budget Cuts

A few respondents mentioned funding and budget cuts.

“I only wish that family support got more funding for people who need it in times when things are tight. They should not do any cut backs on funding of money, we need this sometimes.”

“Taking away certain benefits to the children is wrong. I think you need to reconsider this decision. Families with children with disabilities need that extra help. Most of us are stay at home parents, we do not have that second income.”

Dissatisfaction with Services

A couple respondents mentioned that they were dissatisfied with services.

“We have no problem at all taking care of the children we have. The only conundrum is the red tape and all of the laws we must bandy around. When the system, if it ever does, gets its act together, it will be better for all of us.”

“Is willing to handle the needs my child presents. It is also very difficult, for my child, to participate in activities in the community. We would benefit from being able to take an assistant along, so we can enjoy family time with our child.”

WASHINGTON

Approximately half of all survey respondents from Washington wrote qualitative comments. These comments are summarized by theme below. Respondents most frequently mentioned dissatisfaction with services, followed by case management, communication issues, and respite services.

Overall Dissatisfaction with Services or Inadequate Services

Respondents most frequently reported being dissatisfied with services or that they were receiving inadequate services. Common issues included: needing therapy (i.e. physical, speech, OT, etc.), long waiting lists, needing more hours for services, lack of services in general,

“I think that the respite workers that DDD provide need to be ‘checked out’ better and any negative information on them should be made known to the families! We had someone hit one of our children and later found out that she (the respite worker) had previous marks against her. At first our caseworker was very sympathetic and promised to help...but after the respite worker went to the caseworker and cried for half an hour, the caseworker took her side and didn’t have the nerve to call us. This person who hit my child still works for DDD! I would never trust anyone else sent to us from DDD!!! We found our own person and we were just lucky that she already was contracted through DDD.”

“We have been on the Cap Waiver waiting list for over two years. I am disgusted that my special needs child can’t get the services he deserves. Every time I call, I am told there is no change. I am saddened by the fact that the lawsuit was overturned.”

“We are a family that is very dissatisfied with the services we receive from the DDD for E. From the time he has been placed in our home at 18 months, the DDD has never adequately provided the services and supports he requires. Now at eight years of age as his needs have increased and the services and supports provided by DDD have decreased, our family is in crisis. E. has not had any in-home supports or respite provider paid for by DDD since August. There is no childcare available for E. in our community. And there have been no dollars for in-home respite. We have five children; three with disabilities and we desperately need more help or fewer children.”

“We moved here two years ago from a state that absolutely spoiled us...asked us if we needed a wheelchair, asked us if we needed new equipment, offered us nursing hours so we could more easily attend to other aspects of our lives, offered us overnight respite at a pediatric nursing facility so we could get away for a few days and feel confident our child was well cared for. Here in Washington we get nothing from the state. Any help we get is from the school. DDD offered us respite for one year (because we still financially qualified at that point), but even then they said that it would be illegal for the care provider to feed our child because she’s G-tube fed and that is a nursing skill. I asked for a nurse, then, but was told that she didn’t qualify for that because she isn’t trached. So we over qualify for one care and under qualify for the other. Quite a big crack in your system, Washington! So even when we did qualify for care, we could only leave for one to two hours at a time so we could get back to feed her...not much help. Now that we no longer financially qualify for that (because we live in [County]) and still have to pay all of our other bills – I had to go to work), we haven’t heard another word

from the DDD. Until I got this letter I didn't even know that we were still on their list. I don't even know after all of this time if we still have the same case manager."

"I feel there are not enough resources available for children with severe behavioral disabilities especially when your child can't communicate. There needs to be more training seminars for parents and support groups out there that are more local. A lot of services out there are not properly trained to deal with a child like mine so we are turned away because they feel like they can't help or control them."

"My greatest concern is that Spinal Bifida is not categorized within the state. My son doesn't qualify for some services because he is smart. It doesn't matter that he is confined to a wheelchair and needs help with most activities. According to the state a child with one seizure a year that isn't even serious can qualify for things my son can't. I think the state needs to re-qualify according to the type of disability not just the standard CP., CF., mental illness, etc. There will be many more children with Spinal Bifida that should qualify for services in the future."

"I believe the reason I am dissatisfied with the services provided is mostly because of two things. First, the age of my son. There are no adequate services here in our area. The services and money here are for young children or for adults in the community. There are no social supports, training or teaching (outside of the school) for the disabled from about age eight to the 18-21-year range. [Provider] has some opportunities for socialization that is volunteer. Unfortunately, my son needs more supervision than that program can provide. I am also not thrilled with the choice of respite/home care providers. I think I would use the service more if I thought the people providing care for my son had a higher IQ than he does. If you pay people a living wage, you may get people who are more qualified to give care to the disabled."

"I appreciate DDD but it doesn't extend its hand fairly to children with mental behavioral disabilities. So my child was dropped at age six. He still needs help. Our family still needs respite care and help transporting him to doctors, etc. He is very hard to handle and violent at times. It is sad to be so limited and exiled."

"I like the service provided with respite care but would like more hours. I would like more help finding services for my son. I hate being on a waiting list to get more services. It seems like I will never get more support with the DD program."

"My son has been on the waiting list for any services for over four years. We receive nothing including respite care to provide for our son's needs. My husband has taken a high-income job out of town and is gone every week leaving me to care for our children myself. We receive no respite care. I have a friend who moved to Washington just two years ago and receives everything from diapers to 60 hours per month respite care for her son and her husband is at home! To pay for M.'s services we need to make more money. Insurance only pays for a very small amount of Speech and OT. M.'s needs are extensive, yet as punishment we are disqualified from other services. I am so outraged that hearing the letters DDD is upsetting to me. If nothing else, all I have asked for is respite care dollars and even that isn't happening! I need a break sometimes too!"

"Have not been impressed with the system that currently is available."

“Don’t get me started; as an RN myself; this system stinks and flounders in it’s own quagmire of paper and bureaucracy. Delegate to the parents; most of us love and want the best for our kids and come hell or high water we try to make that happen.”

“We have had a very poor experience with DDD. Case managers are poorly trained and only tell you what cannot be done. Dr. [name] – the ‘behavior specialist’ is a joke. He makes recommendations that would be impossible to implement in a normal family setting (we were later told by DDD staff, after we complained, that ‘we have to use him first because he is cheapest’). Families are not presented with options and allowed to choose the best options for their family. You only find out about resources by networking with other parents. The whole system is sick and nonfunctional. Families whose kids act out in the presence of the case manager get more services than families whose kids don’t happen to act out at that time. There is no provision for DD/mentally ill kids.”

“I don’t feel like we’ve benefited from this program at all. We haven’t received any help pertaining to their needs.”

Case Management

Several respondents mentioned case management services. Approximately the same number of respondents were satisfied with case management as those who were dissatisfied.

“Overall I am very happy with my case manager. She understands my needs and is always available to me.”

“Our case manager is wonderful.”

“My case manager is very helpful, respectful and understanding. I think she is great and we are lucky to have her help.”

“I have nothing but good results with our services and caseworker. She is excellent, always there for us. Always working for us.”

“I am completely satisfied with DDD and my case manager. They are prompt to return calls and for appointments.”

“I like my caseworker. She’s been with us for a long time and is always helpful. She is willing to answer any of my questions no matter how silly I think they are.”

“I love our case manager. She is excellent! She handles all of my concerns quickly and professionally.”

“[Case manager] has gone above and beyond for us – we’d be out on the streets without her help.”

Several respondents indicated that they were dissatisfied with case management services. Problems included: poor communication, lack of follow through, and large case loads.

“My caseworker contacts me only once a year to update paperwork and I quit calling DDD because they usually cannot help me. Other than receiving our initial MPC and Medicaid, we don’t know what else is available to us or how we can better use the

programs we already have. Currently I have been without a caseworker for six months. I would appreciate one!"

"I am always unclear as to whom I need to talk to, depending on what services I have or are about to have. This is due to infrequent personal communication with my case manager (it would be nice for her to keep in contact and check on us) – also due to restructuring of system and change in personnel. I often have old phone numbers and old names because of such infrequent contact."

"A different case manager every year that doesn't know anything until he pulls up in your drive and opens your case file? And tells you what a wonderful job 'you're doing' why, yes I am doing 'your job'."

"Our case manager did not inform us of some services (respite care, diapering supplies and help for incontinence problem of client) until the client was over three years old. We did not meet our caseworker until the client had received some DDD services for 16-18 months! Her assessment of our child has mistakes in it – i.e., this child who cannot walk alone is supposedly able to bathe unassisted. We rarely hear from DDD unless they want to reassess our child in order to try to take the services received away. We have to try to fight to keep them because our child was not diagnosed with a standard syndrome or retardation – yet."

"Last year it took me, my son's teacher, his therapist and family support person to leave a message for his caseworker before she finally got back to us. They are overworked and have too many clients to give the support needed for every family!"

"I cannot trust T.'s case manager to follow through on the requests I make regarding respite care as well as other services I have asked for. I usually have to follow-up on them myself!"

"The location of our case manager is very convenient but we have never met her and she has never met my DD child. She never offers ideas on what's available in [city] for autism. I have found everything."

"We have had many case managers over the years. I am not even sure who replaced our last one."

"The biggest problem I have experienced is when my daughter gets a new case manager. She has had three to four since enrollment."

"My son's case manager has been changed so many times in the past couple of years that I lost count. It is very important for our family to stay with one case manager – one person who will continue to understand our situation."

Communication

Communication was a frequently mentioned topic area. Most respondents noted communication problems with their case managers and lack of information about services.

"While I know case managers and financial payment people are overwhelmed with cases, I find it very difficult to be sympathetic. My providers are not paid enough hourly

to keep them and happy. And although I do not want excessive communication with DDD to bog me down, a current list of providers available in my area would be REALLY helpful and hearing from my case manager more often than 'It's time for a review' might be encouraging/supportive."

"I believe DDD has the policy if the customer doesn't ask – they don't tell – meaning unless I know specifically what kind of support programs are available to me, they don't just 'offer' to tell me what support is available."

"My caseworker usually does not respond promptly when I leave a message, or have a need around services/information."

"DDD support staff, case managers and supervisors rarely respond to tough questions. They do not call back with answers, lack follow through. I always have to place follow-up calls. Follow-up in general is poor."

"It gets very frustrating when you call to talk to the case manager and they're not in and then you go to the supervisor and they can't really help you because they know nothing about the case."

"I am overall happy with the services I receive for my daughter. I would like to know more about what is available to my child. I feel they (DDD) don't want to give me a lot of information or maybe they are just overworked and don't have the time."

"Communication is the key! I'm sure that there are other services available to S. that we're not even aware of. Whose responsibility is it to make sure we know how to access it? The case manager? Community Guide?"

"We feel we need an advocate to help us identify and access supports that are out there for us."

"Would like to see more information on classes, seminars and get-togethers for parents of children with disabilities. I would also like to see info on home schooling a child with disabilities and single parents taking on this job of caring for a special needs child."

"Don't feel that I am very informed about services and opportunities that are out there. I don't know any other mothers that are in my situation. And most of all, I don't know what I can start to do now to ensure that we have a bright future. My child has a disability but we/she should not be limited to living 'day by day'! What can I do to further my education to provide us with stability? What programs should we participate in to build on her strengths so she can live her life to her fullest potential? Who do I look to for answers to my questions?"

"Because of the services being scattered through different agencies, I still need to run around looking for different services for my children. I am also never quite sure when I have used up my family support dollars and what I can use it for."

Staff

Several respondents made comments about staff. Most respondents who commented on this issue were dissatisfied.

“Personal care people are so hard to find and train.”

“It has been extremely difficult for others and myself on the island to find a provider for in-home services.”

“Finding care providers are always difficult. The referral services usually do not provide good resources – from my past experiences. Most of our providers are friends and people we met. Providers usually don’t stay in a job for too long. The turnover is disruptive to families and finding someone new takes time. I found myself settling on less qualified providers just because there is no other available. I believe the low hourly pay is an important factor.”

“There are no reliable providers – newspaper ads, dozens of calls to agencies and now even a union – all fruitless.”

“The problem with the number of care providers and lack thereof lies in the hands of one person who processes all of the applications and background checks, which results in an overworked and stressed-out rude person to deal with when inquiries are made concerning someone we have requested to be a provider. Also, this results in a severe lack in service providers for one to two month periods (sometimes longer than six months) of time.”

“The help given by the community support person was not helpful as I felt the person tried to relate my child’s condition to her own child. I sometimes feel that there is no one else out there with a child with moderate to severe mental retardation or a support provider who understands the condition.”

“I feel that respite and personal care providers need more training to meet specific needs of special needs children. Taking care of these children require skills in areas of communication, interpersonal, behavioral techniques, reward systems, how to modify tasks, homework, how to help with ADLs, feeding and nutrition issues, anger management (helping child cope with anger) and many more.”

“I feel that Medicaid providers need and should be paid more than \$7.68 an hour so that there is less turnover. Our kids deserve more long-term relationships.”

“It is very difficult to find in-home providers in our area. Unfortunately, the pay just isn’t competitive.”

“We also feel the in-home providers should be chosen by us, like through some kind of screening process and they should get paid more.”

Overall Satisfaction with Services or Agencies

Several respondents indicated that they were satisfied with services.

“We appreciate DDD!!”

“Keep things the way they are. My English is limited but I’m very grateful to see how much you care for children with disabilities and their families in Washington State. Keep on doing the good work.”

“Overall I’ve enjoyed services through DDD and my home care provider. I’ve been seeing my child improve each day with help and support from DDD and [provider].”

“I am completely satisfied with DDD and my case manager.”

“The services our family receives are so helpful to us. It makes all the difference in the world to us to have the support needed to care for my daughter. We are very thankful for the benefits she receives”.

“Thank you, DDD and [case manager] helping me to be able to keep my very involved foster daughter, blind and autistic, for the last five years happy and healthy with the assistance I need to keep sane and healthy myself.”

“These services do make a difference. It is very difficult to find quality care for A. Her syndrome is rare and totally multi-handicapped. Without DDD and my daughter (A.’s caretaker through DDD), we probably might not have survived over the years. I would like to extend my thanks and gratitude for the services provided.”

Family Support

Several respondents commented on family support.

“J. has qualified for family support funds for three to four years. We have probably used a total of \$500 in all those years. The balance remaining of his funds go back into the pot at the end of each year. Through his school we have found a computer system that we think will work well for him. He will learn but it will also be fun for him. He loves computers but does not have the motor control to push keys or move a mouse. We would like to incorporate this system into our home at a cost of approximately \$500-\$700. We were told that if this were his only means of communication his funds could be used for this. It looks like ‘his funds’ will go back into the pot.”

“I am very satisfied with the supports for my adolescent son. I would like to be able to utilize my family support dollars a bit more flexibly (use MPC for respite/personal care and FS for equipment, therapy, supplies and not for any respite). In the overall picture of how DDD allocates money/support, I am frustrated. My child’s needs are great (deaf, blind, developmentally delayed - needs a lot of support) yet, many families I know have children with even greater needs (behavior issues, not a great school program teaching appropriate skills) and they have nothing – how can there be equity and fairness in how resources are provided? Also – when will there be a major recruitment/marketing drive to entice providers – many families have the MPC or family support dollars – but no providers – pay is awful (I know, I know – legislature needs to allocate more dollars), no

benefits, etc. – yet, regardless of legislative fallout – it is the most significant barrier to families feeling supported and having relief.”

“We have been using the family support program for about three years – we are thrilled with it! We are able to provide our daughter with those ‘little extras’ that make all the difference!”

“I wish that our family were not always so restricted on how to spend Family Support dollars. Example: being able to use for mileage reimbursement to medical appointments. We live in a rural area and transportation a hassle. Also wanted to get our daughter oral motor therapy toys and tools. Having to run the gauntlet on that.”

“My son has been on the waiting list for family support services for five years. I only get emergency respite services; last summer was the first time.”

Respite

Several respondents mentioned respite. Most of these respondents were dissatisfied with respite care. Respondents reported that they have problems with insufficient respite hours, lack of providers, and a lack of adequately trained providers.

“I mainly just use respite care for my daughter, which has really helped out.”

“My daughter’s case manager is wonderful, as is our primary respite provider.”

“I don’t believe it is fair for a foster parent to lose respite hours if there’s no place for a child to go on a regular basis. It isn’t fair. If our days aren’t taken, we should get paid for them since it’s days we have earned. Caseworkers get their days off every weekend. Us foster parents don’t have that option.”

“Approved hours should be a priority.”

“However, I have asked several times for assistance in finding both Medicaid personal services and in-home providers but have gotten no response. The need for in-home respite providers is critical. If I am to work, I need reliable respite care that will be involved in the social, physical and emotional well being of my child. We need better trained and well-paid qualified individuals desperately.”

“I have had little to no support from any state agency, and only got respite after it was ‘discovered’ my son had been ‘lost’ in the system for three years. It’s only my intervention and knowledge that guides his support. Twenty-four hours is nothing when you have no other help and have to pay for specialized day care as there are none designed for children with special needs.”

“Respite care has been nice but not consistent enough to make a difference.”

“It would be nice if we had a list of respite care providers in our area. Because we are not given a lot of hours of support, we need someone who only works for us sporadically on a part-time temporary basis. Most providers we know of want fulltime work with benefits and therefore are not available for short time temporary work. Also the dollars allocated for respite care don’t allow for decent wages for the provider.”

"I could use a little more money and hours for C. I do use my respite care up fast."

"I am in need for more time for work and getting respite hours so I can actually have a break other than work. The current number of hours I receive (96) is not enough to meet my current work needs. I have had to use sick leave and just be short of 40 hours due to not having enough hours for my child's caregiver to pick him up. At this time there is absolutely no time left for me to shop, do laundry or just do something for my 'mental wellness' because I have to use all 96 hours for work so I can have a full paycheck."

Home and Placement

A few respondents mentioned home or placement issues.

"I am very concerned about the future of my child. He is severely mentally disabled, has uncontrolled seizures and is incontinent. He was placed on the 'list' for voluntary placement three years ago but nothing came through. My previous caseworker was very honest with me and told me placement for a child like mine is very difficult if not impossible. He is over 200 pounds and loves to eat. I worry about him if he is placed in a group home if he can be safe with his current disabilities. I am in favor of remodeling [institution]. My son is one that would 'thrive' in an institution."

"I don't know if DDD has any role here but several years ago Washington State did away with group type homes for extreme behavior of kids. I believe the limited foster care program kids can use them if out-of-home placement is necessary is not an option for all people that need out of home care. The group home setting is a much better plan for some folks with special needs (because of structure and much needed boundaries, not being moved from home to home). I would have to see more places like [group home] as it meets needs that a regular or special foster home could never meet for some folks."

"G. is a very difficult child; however, and our repeated requests for out-of-home placement are largely ignored by the DDD bureaucracy."

"My son is severely autistic (non-verbal and needs to be watched over closely). He is a very large 13-year-old. I need a group home or some type of facility where he can live peacefully and happily. I am absolutely exhausted from taking care of him. I love him to death but his needs are constant and tremendous and it is more than I can handle anymore."

Employment

A few respondents reported that it is difficult to balance caregiver responsibilities and employment.

"I would like to say thank you for DDD to support my daughter. I can hire the provider to take care of J. I can have some time for rest. I'm a single mom. I need to take care of two kids. I need to work full time. Some times I feel very tired and mad."

"The need for in-home respite providers is critical. If I am to work, I need reliable respite care that will be involved in the social, physical and emotional well being of my child."

"I continually battle financially to keep myself afloat and a home over my son's head. If I quit my job, then I'd get help? What kind of sense does this make?"

"The lack of an in-home care/respite provider seriously impacts our ability to seek employment opportunities outside the home."

Health Care

Several respondents wrote comments about health care issues including, insurance, medical, and alternative medical care.

"The state of Washington Insurance Commissioner has allowed our insurance company to put a cap on durable medical supplies on our coupon then picks up the difference but limits our choices for standers, wheelchairs, etc. We feel that we get a substandard product by the limitations of the state – i.e. for example, we needed a new wheelchair for our son. Since our insurance has always covered it up until now, we had no idea what it would take to get the state to pay the difference. I had the head of the Orthopedic Department at [hospital] write a letter saying we needed the lightest wheelchair available. The state disagreed and now my son has an incredibly heavy wheelchair that he needs to push himself and I must lift. This will lead to shoulder problems for him in the future and probably more surgeries that might have been avoided."

"We are losing our insurance benefits the middle of May. Should we get Medicaid for C.? It's confusing to us on what's based on income and what's not, and the funds always seem to be frozen when I call."

"My concern is Medical coupons. My daughter does have insurance through my husband's work but there are things that insurances don't cover that could get covered through Medical coupons. I would like any information if there have been any programs available that I can get my daughter involved."

"I would like to see more education and information about homeopathic and naturopathic medicine and the benefits of these practices for children with disabilities to be able to have funding for what medical insurance does not cover. We have the greatest results from using these methods and think that other parents with children with disabilities would benefit from these approaches but we have had to pay out-of-pocket for a lot of these expenses and it would be nice to have funds for compensation for something that is so effective."

"I am thankful for the available services and the funding provided but I feel that the importance of nontraditional therapy is being overlooked and no funding category is currently available."

Education and Training

A few respondents indicated that they were dissatisfied with education and training.

"Our child is currently home schooling. We are not able to secure a satisfactory placement at a public school."

"My community and school are horrible with my daughter. I wish I had a lot more help with them so I could help her. It's bad enough to be disabled let alone put up with people that won't help her excel or be a part of what everyone else is."

"Daycare and private schools don't offer much for special needs children and the public schools program is (like many) understaffed and under funded."

Transportation

A couple respondents reported that they are dissatisfied with transportation services.

"We do not have a car and some of the places to go to are far away. Plus, I have a disability called Crone's Disease and it is very difficult taking a bus."

"We need help with transportation desperately."

Recreation Activities

A few respondents wrote comments about recreational activities. Most of these respondents were dissatisfied with the availability of recreation or socialization activities.

"My daughter has problems with social skills and once in a while she would like to go out with friends but unfortunately we do not have the money teenagers would like to have on them to spend. I have asked for an increase but \$12 more a month just isn't enough."

"I do wish that there were more activities for kids with disabilities."

"Activities are needed within the community that provide stimulation and mental growth."

"During the summer usually my son or daughter has no activities they can be involved in due to the expense of the programs. Every time I inquire about the [local recreations center], I'm always told there's a waiting list that they have been on for about three years."

"My son was able to go to the park, play areas, etc. for a while. His provider company quit paying the mileage and DDD wouldn't authorize transport monies. His caregiver basically became a babysitter at my home. I feel that if he had been able to take my son into the community, it would have been better for all of us. Once a week would have been fine. My son has social skill problems and it would have been beneficial for him to have more community exposure."

Transition Issues

A couple respondents wrote comments about transition issues.

"Recently my son and I went through a transitional program since my son was 16 years old. The program was excellent. We made a picture book of all his likes, dislikes, goals, future finances, etc. Two wonderful ladies came to our home in three visits to put the book together. I was extremely helpful in many ways."

"Our daughter will be 15 next week and we'd like to begin receiving information as to supports (vocational/recreational/living arrangements) and options as she becomes an

adult. We rarely have a need to tap into DDD resources but feel the transitions among school, semi-independent living and job is one of critical importance, and hope that our case manager will begin sending this type of info when the time comes.”

“The transition from Birth to three and three to five is a very hard transition and they are not very willing to update their ideas or incorporate a broader view on these children’s abilities. Their expectations are very low in my opinion.”

Family Members a Paid Staff or Case Managers

A couple respondents wrote comments about family members as paid staff or case managers.

“I think a sibling should be eligible to become a respite or MCP at age 16. My older children take care of my disabled child quite a bit as the MCP is unable to come in as much as I need her to or the hours I need. If I was able to access those funds that are available to use for MCP, I could pay my children. They are the most experts at taking care of my disabled child. Other kids get jobs at age 16 but mine will not be able to because they are needed at home. It would be nice if they could be paid for their work. It is very difficult to find a quality care provider who I trust. The wages are too low to get quality care.”

“I am unemployed at this time and going to school so I wish I could be my son’s respite or personal care provider and get a part-time job for he is going through medicine changes and school changes which had caused extra behavioral issues.”

Funding and Budget Cuts

A few respondents commented on the impact of funding and budget cuts on services for their child.

“The state of Washington has cut back on support for children with disabilities. Our hope is that the state will find funding to help families who have a family member with a disability. Without services, we may not have been able to keep our son at home with us due to his disability.

“DDD is currently trying to eliminate benefits for recipients by any means possible. This is causing a great deal of anxiety and costing money for affected families to be diagnosed again.”

“It is sad that all the services seem to be cut or frozen. It is hard to be a good case manager when there is nothing to offer (no fault of theirs).”

WYOMING

Approximately 41% of survey respondents from Wyoming wrote qualitative comments. These comments are summarized by theme below. Most frequently noted were staff issues, case management, and transition issues.

Home

Several respondents talked about needing accommodations to their home, in addition to delays in getting those accommodations, high costs of equipment, and other related issues.

“My biggest problem is that there is no profit cap on specialized equipment. Three years ago we purchased an adapted swing set for \$1800. Our daughter’s account was charged approximately \$5200, which totaled a profit of 288%, or \$3400. That is a lot of money to process paperwork. I did everything including getting the bid, there was not a lot of work left. Recently it was close to the same scenario, but the profit was 33% or \$1386, for what amounts to a couple of hours of work. I would request an immediate change to the rules that caps profit to an hourly fee or \$100 whichever is greater, or some other alternative to bring these exorbitant expenses under control.”

“There appears to be no help available to the house or at school. We asked how to keep him safe during the winter he always go to the heater and kicked it in our bathroom he sticks his finger inside the heater. My case manager measured the heater so we can get a guard but until now no results. “

“I wish there were more sources of organization to help us purchase different equipment like wheelchairs, special beds or modifying adaptable equipment etc. My son has an air alternation pressure mattress on a hospital bed, which is wearing out but can't get a replacement for it.”

One person fervently expressed that she intends to keep her child at home instead of in an institutional placement.

“Family or no family, I would pour gasoline on my head, light the match and march through the gates of hell to keep my child at home!”

Caregiver Employment

The challenges faced by caregivers who work, especially single parents, was mentioned by a couple of respondents.

“It would be nice if there were more resources and services for single parents of children w/ special needs! The state claims that respite will not be increased so a parent can work. How do we work to care for our family if we don't have someone to care for the child with special needs while at work? Do we stay home and collect welfare? Either way the state pays.”

Education and Training

A couple of respondents indicated that they are dissatisfied with their child's school.

"If this is suppose to be a school for the developmentally disabled how come normal child that simply do not want to behave go to school there? It worries me I feel this puts our children at risk for abuse from other children, etc."

"It would be really lovely if the school had to let parents fill our one of these surveys. They'd be in hot water. Not happy at all with schools."

Recreational Activities

Several respondents noted that they have difficulty acquiring adaptive equipment, accessing general programs like music and dance, and getting information about available programs.

"We struggle trying to get durable equipment that would enable our child to become more a part of her social circle i.e. manual wheelchair that would allow her to visit with school friends whose homes are not accessible to her power chair, take trips to grandparent's homes and other relative's homes."

"My child was denied access to a local dance group and there aren't any programs that I could find for her in that area of recreation. I'd like to see more recreation programs in place that take into consideration the unique needs of the DD. Our local parks and recreation does a fine job here, but if we pooled our resources (mainly students) we would have many more options. Cost of participation is another factor. I don't know if the waiver of respite programs could cover these expenses, but if not, I believe it should be considered. "

"I would like it if our case management was more knowledgeable in the area of community activities such as sports, [organization name] and other activities such as community based plays. I asked about the [organization name] and there was not a single person that knew who to contact or where. "

Communication

Several respondents mentioned that they do not receive adequate information about services and resources that are available for their children.

"The biggest problems we have are with the [provider] group they are not informational and in my opinion try to hide what services are available. They act like we are trying to get the most out of the system and all we are trying to do is make it where we can make a decent income and not have to pay \$180,000.00 in medical bills!"

"It is like pulling teeth to find what resources are available, how to get them and what the guidelines are."

"We were not made fully aware of the support we could have received until three or four years ago, even though our child was diagnosed when he was five. It was discovered that a part of his brain did not develop, which caused learning delays in many areas. He started receiving services when he was 18. It would have been very helpful to get this

support when he was diagnosed at five. The forms we receive are often difficult to understand and trying to visit with someone in [city] is difficult to do. I have often left messages but have not been contacted. It has been frustrating I know the people in [city] must have a tremendous work load – but when you leave messages they often go unanswered. When we have been unable to send the requested information on something because we did not understand - then we are made to feel badly about our ignorance. It is sometimes frustrating and hurtful. The people on this end seem more sensitive toward our situation and our individual circumstances.”

“I feel we need more information on what services and programs are available for them as they grow older and leave school. More information on financial help for them when they are ready to be more on their own.”

“It is difficult to get information on the status of our children on the adult waiver waiting list. We have no idea when (if) funding will become available for them. More direct contact with and information from state DD programs would be helpful.”

Transition Issues

A number of respondents talked about transition issues, in particular, the transition from the child waiver to the adult waiver noting that they were satisfied with the child waiver, but are hesitant about the adult waiver. Several people also reported that they are concerned about funding problems, wait lists, reduced service array, and lack information about the adult waiver program.

“Our son is on the children's waivers but we are fast approaching adulthood. We are hearing that funding is a problem and we are very concerned. We are so pleased with the children's waivers, so why are we being left out just because our son is close to an adult. I feel the services and support are just as important for adults as for children. Just because they are a chronological age doesn't mean they are at the same age mentally (in fact most are still children mentally). I would like to see both children and adult funded the same or maybe more since adults need all day care.”

“I would like to see more help on the transition years and helping parents understand it. What are our options when the child could benefit from a more of a group setting of those who are on their level and there isn't anything around your area?”

“I am very concerned about the long waiting list for the adult waiver. My daughter has been on the children's waiver since 1994 and now she is suddenly going to be totally without services. Her brain injury has not gone away – only the services. It doesn't seem right. “

“Our son is going to be 21 in January. We know he will be on the waiting list for some time. It breaks our hearts to think he will forget all that high school and [provider] has taught him about working, socialization etc. and that he will have to go through all of the work support over again because of the fact that he can not go right onto the adult waiver. Our family will also suffer because we will not have respite care. Our son is a teenager in his mind and body and does not want to be home with mom and dad. He wants to be in a home of his own, taking care of himself.”

Case Management Satisfied

Several respondents noted that they are satisfied with case management services, while a couple of people responded that they needed more information from their case manager about available services, and one person mentioned that case manager turnover was a problem.

"I depend on these services to keep my child with me. Without them I could not do it. [Name] is my child's case manager and she is excellent. She visits my child at school and let's me know how he is doing."

"Our case manager is fantastic. I totally feel like she is in it to help families and people with disabilities. She is knowledgeable, efficient, compassionate and respectful. I wish everyone could have the experience we've had with a case manager."

"Our case manager is an awesome woman who is highly informed and active in our family."

"I would like it if our case management was more knowledgeable in the area of community activities such as sports, [organization name] and other activities such as community based plays."

"We have had three case managers in one and a half years of services."

Staff

All comments related to staff were negative. People responded that insufficient staff training and qualifications, limited service array, and lack of providers were all major problems.

"Better screening and education of service providers seems warranted. Some providers seem to have little interest in providing care but see this work only as a way to earn a good wage."

"Limitations of what service providers can do should be removed. Why shouldn't home care be able to change/make-up a bed. Everything they do helps me and allows me to be more available for my child. The stress of dealing with a special needs child while trying to hold down a job so that I can keep a roof over our heads is so overwhelming. Let the service providers help any way they can! Provide training to respite care givers so that they understand a) what they are in for and b) can do it better! They (respite care givers) need to be trained sot that they are providing a help to the over all day. For example: start dinner instead of feeding a snack right before dinner time. The snack inhibits my child's appetite at dinner and causes me added frustration when my child proclaims hunger at bed time! It seems like a lot of the respite-care providers use the job to get through school. While some of them are very good, some come to my home already frazzled from an over-whelming academic schedule expecting to put in a video and do their homework for \$11.00 an hour! Unacceptable! Someone should weed these people out before they waste everyone's time getting approved and on the schedule. This system is obviously broke. Also, there are not enough good providers available especially at peak demand hours. Please do more to recruit good people."

"I am having a hard time trying to find a respite provider that can take my daughter during school. I'm also having a hard time finding someone for homemaker. It seems

like there aren't enough people certified for these positions. I'm having to recruit my own people and that is hard to do. The people that are already certified are all busy."

"My child does great with res-hab provider care. However, I feel that these providers seem to have the upper hand they know the families are in a bind- so they work when they want and they don't work when they don't feel like it. They take time off when it's best for them- they cancel days at the last minute or with very little notice. Mainly because they know we have no other options so we have to put up with them. I realize it's a stressful job but they don't eat sleep and breathe these kids like their families are. I feel there should be more accountability for these people: write ups, reprimands, dock days warnings something to make them take the commitment seriously. They know they work for the state and not the individuals so there is nothing that requires them to commit fully. And no consequences what so ever if they don't. My child has been on the waiver for five years and rarely spends all his dollars because providers are always quitting or taking time off, or working other jobs or deciding they only need one day a week instead of two. Whatever they know my option is to have no one and I am so ready to just say forget the whole thing because it's not worth my time to stress over a provider."

"I do not have trained qualified people who are knowledgeable and experienced to work with my child with autism. The money is there but there isn't anyone to hire. There isn't anyone for the case manager to recommend. So my child is not in the community as much as he could be. Mostly he's in front of the television and computer."

Respite

A few respondents mentioned that they have difficulty finding qualified respite providers.

"We need qualified respite care givers in the area – there are none."

"The one major headache and problem is to get respite workers certified the process takes way too long. It is cumbersome and extremely frustrating causing would be respite workers to forego there certification as a result I am now paying out of my pocket to have some providers while I go to work and they wait for the state to process their certification."

Overall Satisfaction with Services or Agencies

Most respondents seemed to be satisfied with services or agencies.

"My son is doing great due to all his rehab and respite workers and school and his therapies – thanks. I depend on these services to keep my child with me. Without them I could not do it. [Name] is my child's case manager and she is excellent. She visits my child at school and let's me know how he is doing."

"This child is pretty easy to do things for and get things for him. Having the assistance we get allows him to get into the community a lot more. He really enjoys the people that help him."

"Super peer support programs in school, adaptive P.E. youth group. We are fortunate to have exemplary providers for our son. I feel with this support he will be able to live in the

community in his own apartment when he is about 25. His job experiences will help him and are a priority with us now. I am very thankful for the services received I am very thankful for the people providing these services. I am very disappointed in the recent changes of scoring ICAP tests.”

A few were satisfied in some areas, while some people were dissatisfied overall. Lack of services/providers, needed adaptive equipment, and qualified staff and case managers were most frequently noted.

“Overall we have been very pleased with everything except SSI.”

“We have been very thankful for the services our daughter has received. The hardest part is finding people to do the services she has been approved for. Housekeeping has proven impossible for us to find someone dependable. It is difficult to look at a list of people once or twice a year to try and get providers and families together.”

“I am very disappointed w/all services in our area (or rather lack of services).”

“I feel there is a great need for more service providers so there are some choices as well as continued service when a provider needs to be gone. “

“We live in [name of area] where there are few services available to us as far as respite, res-hab, etc.”

APPENDIX A

Summary Tables of Survey Responses

Table B - Characteristics of Respondents: 2002 Data

STATES	Total %		State Avg.	AZ		CA-RCOC		MA		SC		SD		WA		WY	
Number of surveys				347		923		370		104		171		476		187	
Age:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Under 35	534	20.9	21.5	137	39.5	164	18.0	44	11.9	25	24.3	29	17.2	101	21.3	34	18.2
35 to 54	1,825	71.3	71.1	191	55.0	654	71.9	303	82.1	65	63.1	137	81.1	339	71.5	136	72.7
55 to 74	186	7.3	6.9	18	5.2	84	9.2	20	5.4	11	10.7	3	1.8	33	7.0	17	9.1
75 or Over	14	0.5	0.3	1	0.3	8	0.9	2	0.5	2	0.1	0	0.0	1	0.2	0	0.0
	2,559		n = 7	347		910		369		103		169		474		187	
Relationship to consumer:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Parent	2,463	96.3	95.4	333	96.0	891	97.8	359	97.0	93	91.2	165	97.6	448	94.9	174	93.0
Sibling	3	0.1	0.1	1	0.3	0	0.0	2	0.5	0	0.0	0	0.0	0	0.0	0	0.0
Grandparent	74	2.9	3.5	12	3.5	15	1.6	6	1.6	6	5.9	3	1.8	21	4.4	11	5.9
Other	18	0.7	1.0	1	0.3	5	0.5	3	0.8	3	2.9	1	0.6	3	0.6	2	1.1
	2,558		n = 7	347		911		370		102		169		472		187	
Respondent is primary caregiver:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Yes	2,489	97.9	98.2	339	99.1	888	97.6	357	98.3	102	99.0	167	98.8	456	96.6	180	97.8
Household Income:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Below \$15,000	549	22.8	24.0	85	26.6	195	22.7	63	17.8	39	41.1	25	15.5	107	24.2	35	20.0
\$15,001-\$25,000	453	18.8	19.0	70	21.9	191	22.2	35	9.9	23	24.2	38	23.6	68	15.3	28	16.0
\$25,001-\$50,000	633	26.3	28.2	76	23.8	183	21.3	94	26.6	18	18.9	66	41.0	134	30.2	62	35.4
\$50,001-\$75,000	382	15.9	15.3	43	13.4	121	14.1	63	17.8	6	6.3	20	12.4	88	19.9	41	23.4
Over \$75,000	390	16.2	13.5	46	14.4	169	19.7	99	28.0	9	9.5	12	7.5	46	10.4	9	5.1
	2,407		n = 7	320		859		354		95		161		443		175	
Health of respondent:																	
	n	%	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Excellent	775	30.4	30.0	120	34.8	277	30.6	130	35.3	26	25.2	49	29.0	116	24.7	57	30.5
Good	1,282	50.3	51.6	164	47.5	438	48.3	172	46.7	54	52.4	97	57.4	255	54.3	102	54.5
Fair	432	17.0	16.0	48	13.9	173	19.1	58	15.8	19	18.4	21	12.4	88	18.7	25	13.4
Poor	59	2.3	2.4	13	3.8	18	2.0	8	2.2	4	3.9	2	1.2	11	2.3	3	1.6
	2,548		n = 7	345		906		368		103		169		470		187	

Table C - Services and Support Received: 2002 Data																	
STATES	Total %		State Avg.	AZ		CA-RCOC		MA		SC		SD		WA		WY	
	n	%	n = 3	n	%	n	%	n	%	n	%	n	%	n	%	n	%
SSI financial support	827	34.5	37.1	140	41.1	307	34.8	105	28.9	54	52.9	66	39.1	81	22.9	74	40.2
Other financial support	670	29.4	35.8	44	13.4	93	11.0	212	60.2	20	20.2	105	64.0	124	38.6	72	42.9
In-home support	827	35.1	36.8	154	45.4	227	26.1	128	36.5	26	26.0	43	25.9	151	42.8	98	54.7
Out-of-home respite care	921	39.3	41.8	100	29.9	317	36.3	65	18.5	23	22.8	87	53.0	192	56.8	137	75.3
Early intervention	402	17.4	19.6	82	25.1	169	20.0	37	11.3	40	40.4	41	26.1	17	4.3	16	10.1
Transportation	266	10.9	11.4	52	15.4	104	11.8	24	6.8	16	16.0	17	10.4	32	7.3	21	11.8
Specialized services/supports	1,560	68.1	71.4	287	84.2	508	59.3	246	68.7	59	62.8	146	85.9	168	57.5	146	81.6

Table D - Information and Planning: 2002 Data									
STATES	TOTAL %	STATE AVG.	AZ	CA	MA	SC	SD	WA	WY
Q1 - Do you receive information about the services and supports that are available to your child and family?									
Number of surveys	1,179	n = 7	330	887	359	98	169	465	182
% always or usually	47.3	45.1	44.8	63.4	31.2	49.0	55.6	29.9	41.8
% sometimes	36.9	38.5	37.9	29.4	45.1	32.7	36.7	41.5	46.2
% seldom or never	15.7	16.4	17.3	7.2	23.7	18.4	7.7	28.6	12.1
Q2 - If you receive information, is it easy to understand?									
Number of surveys	2,306	n = 7	309	851	314	90	168	402	172
% always or usually	60.7	59.8	61.2	66.2	60.8	60.0	72.0	48.5	50.0
% sometimes	33.9	34.9	33.3	29.3	34.1	34.4	25.6	42.3	45.3
% seldom or never	5.5	5.3	5.5	4.6	5.1	5.6	2.4	9.2	4.7
Q3 - Do you receive information about the status of your child's development?									
Number of surveys	2,292	n = 7	335	805	311	93	153	415	180
% always or usually	45.9	49.0	60.3	42.1	47.9	55.9	51.6	33.3	52.2
% sometimes	25.6	25.6	21.5	29.6	19.6	24.7	30.7	21.7	31.1
% seldom or never	28.4	25.4	18.2	28.3	32.5	19.4	17.6	45.1	16.7
Q4 - If yes, is this information easy to understand?									
Number of surveys	1,838	n = 7	292	642	238	86	135	288	157
% always or usually	62.3	62.1	72.6	62.1	65.5	62.8	62.2	52.1	57.3
% sometimes	31.7	32.4	22.9	31.0	30.7	30.2	34.1	38.2	39.5
% seldom or never	6.0	5.5	4.5	6.9	3.8	7.0	3.7	9.7	3.2
Q5 - Do you get enough information to help you participate in planning services for your family?									
Number of surveys	2,327	n = 7	325	822	324	95	157	426	178
% always or usually	43.8	47.9	49.2	44.4	31.5	60.0	61.1	32.4	56.7
% sometimes	33.8	32.5	31.4	34.5	37.0	26.3	30.6	35.2	32.6
% seldom or never	22.4	19.6	19.4	21.0	31.5	13.7	8.3	32.4	10.7
Q6 - If your family has a service plan, did you help develop the plan?									
Number of surveys	1,796	n = 7	260	640	210	87	145	291	163
% always or usually	70.0	72.0	74.6	66.6	61.4	67.8	79.3	64.6	89.6
% sometimes	18.1	17.6	17.3	20.0	18.6	23.0	17.2	18.2	9.2
% seldom or never	11.9	10.4	8.1	13.4	20.0	9.2	3.4	17.2	1.2
Q7 - If your family has a service plan, does the plan include things that are important to you?									
Number of surveys	1,770	n = 7	263	616	204	89	143	293	162
% always or usually	68.0	71.7	73.4	61.0	67.2	73.0	81.8	60.4	85.2
% sometimes	21.9	19.4	20.2	25.8	17.6	15.7	14.7	28.3	13.6
% seldom or never	10.1	8.9	6.5	13.1	15.2	11.2	3.5	11.3	1.2

Table D - Information and Planning: 2002 Data									
STATES	TOTAL %	STATE AVG.	AZ	CA	MA	SC	SD	WA	WY
Q1 - Do you receive information about the services and supports that are available to your child and family?									
Number of surveys	1,179	n = 7	330	887	359	98	169	465	182
% always or usually	47.3	45.1	44.8	63.4	31.2	49.0	55.6	29.9	41.8
% sometimes	36.9	38.5	37.9	29.4	45.1	32.7	36.7	41.5	46.2
% seldom or never	15.7	16.4	17.3	7.2	23.7	18.4	7.7	28.6	12.1
Q2 - If you receive information, is it easy to understand?									
Number of surveys	2,306	n = 7	309	851	314	90	168	402	172
% always or usually	60.7	59.8	61.2	66.2	60.8	60.0	72.0	48.5	50.0
% sometimes	33.9	34.9	33.3	29.3	34.1	34.4	25.6	42.3	45.3
% seldom or never	5.5	5.3	5.5	4.6	5.1	5.6	2.4	9.2	4.7
Q3 - Do you receive information about the status of your child's development?									
Number of surveys	2,292	n = 7	335	805	311	93	153	415	180
% always or usually	45.9	49.0	60.3	42.1	47.9	55.9	51.6	33.3	52.2
% sometimes	25.6	25.6	21.5	29.6	19.6	24.7	30.7	21.7	31.1
% seldom or never	28.4	25.4	18.2	28.3	32.5	19.4	17.6	45.1	16.7
Q4 - If yes, is this information easy to understand?									
Number of surveys	1,838	n = 7	292	642	238	86	135	288	157
% always or usually	62.3	62.1	72.6	62.1	65.5	62.8	62.2	52.1	57.3
% sometimes	31.7	32.4	22.9	31.0	30.7	30.2	34.1	38.2	39.5
% seldom or never	6.0	5.5	4.5	6.9	3.8	7.0	3.7	9.7	3.2
Q5 - Do you get enough information to help you participate in planning services for your family?									
Number of surveys	2,327	n = 7	325	822	324	95	157	426	178
% always or usually	43.8	47.9	49.2	44.4	31.5	60.0	61.1	32.4	56.7
% sometimes	33.8	32.5	31.4	34.5	37.0	26.3	30.6	35.2	32.6
% seldom or never	22.4	19.6	19.4	21.0	31.5	13.7	8.3	32.4	10.7
Q6 - If your family has a service plan, did you help develop the plan?									
Number of surveys	1,796	n = 7	260	640	210	87	145	291	163
% always or usually	70.0	72.0	74.6	66.6	61.4	67.8	79.3	64.6	89.6
% sometimes	18.1	17.6	17.3	20.0	18.6	23.0	17.2	18.2	9.2
% seldom or never	11.9	10.4	8.1	13.4	20.0	9.2	3.4	17.2	1.2
Q7 - If your family has a service plan, does the plan include things that are important to you?									
Number of surveys	1,770	n = 7	263	616	204	89	143	293	162
% always or usually	68.0	71.7	73.4	61.0	67.2	73.0	81.8	60.4	85.2
% sometimes	21.9	19.4	20.2	25.8	17.6	15.7	14.7	28.3	13.6
% seldom or never	10.1	8.9	6.5	13.1	15.2	11.2	3.5	11.3	1.2
Table E - Information and Planning: 2002 Data (cont'd)									
STATES	TOTAL %	STATE AVG.	AZ	CA	MA	SC	SD	WA	WY
Q8 - Do the staff who assist you with planning help you figure out what you need as a family to support your child?									
Number of surveys	2,113	n = 7	292	818	235	92	150	352	174
% always or usually	50.5	57.4	60.3	41.3	45.1	68.5	75.3	43.8	67.8
% sometimes	29.1	25.5	24.0	34.6	28.5	18.5	18.0	31.0	23.6
% seldom or never	20.4	17.1	15.8	24.1	26.4	13.0	6.7	25.1	8.6

Table F - Access & Delivery of Services & Supports: 2002 Data									
STATES	TOTAL %	STATE AVG.	AZ	CA	MA	SC	SD	WA	WY
Q14 - When you ask your service/support coordinator for assistance, does he/she help you get what you need?									
Number of surveys	2,234	n = 7	334	734	285	98	163	442	178
% always or usually	61.6	67.9	68.0	47.0	57.5	70.4	89.0	64.5	79.2
% sometimes	28.6	24.7	25.1	35.0	34.0	19.4	9.8	29.9	19.7
% seldom or never	9.8	7.4	6.9	18.0	8.4	10.2	1.2	5.7	1.1
Q15 - Does your family get the services and supports you need?									
Number of surveys	2,362	n = 7	334	823	317	97	164	446	181
% always or usually	49.7	53.6	56.3	49.0	34.4	60.8	75.0	41.9	58.0
% sometimes	39.3	36.4	34.4	40.0	45.4	26.8	23.2	46.0	39.2
% seldom or never	11.0	10.0	9.3	11.1	20.2	12.4	1.8	12.1	2.8
Q16 - Do the services and supports offered meet your family's needs?									
Number of surveys	2,326	n = 7	327	797	315	98	168	441	180
% always or usually	46.5	51.2	52.6	44.0	35.2	58.2	70.8	36.7	61.1
% sometimes	40.5	37.7	38.5	41.3	42.2	31.6	26.2	48.8	35.0
% seldom or never	13.0	11.1	8.9	14.7	22.5	10.2	3.0	14.5	3.9
Q17 - Are supports available when your family needs them?									
Number of surveys	2,272	n = 7	321	764	317	93	164	435	178
% always or usually	43.0	46.4	46.7	43.1	31.2	54.8	66.5	35.6	47.2
% sometimes	43.0	41.1	41.7	42.5	46.7	33.3	29.9	47.6	46.1
% seldom or never	14.0	12.4	11.5	14.4	22.1	11.8	3.7	16.8	6.7
Q18 - Do families in your area request that different types of services and supports be made available in your area?									
Number of surveys	1,077	n = 7	130	446	143	49	46	169	94
% always or usually	44.1	43.2	50.8	48.7	30.8	49.0	43.5	39.1	40.4
% sometimes	41.0	41.7	34.6	37.0	53.1	28.6	43.5	43.8	51.1
% seldom or never	14.9	15.2	14.6	14.3	16.1	22.4	13.0	17.2	8.5
Q19 - If yes, does either the state agency or provider agency respond to their requests?									
Number of surveys	784	n = 7	116	271	123	38	36	128	72
% always or usually	33.3	37.8	37.1	30.6	39.0	47.4	61.1	20.3	29.2
% sometimes	43.9	43.5	48.3	39.1	48.8	34.2	30.6	42.2	61.1
% seldom or never	22.8	18.7	14.7	30.3	12.2	18.4	8.3	37.5	9.7
Q20 - If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?									
Number of surveys	1,117	n = 7	158	360	160	57	91	212	79
% always or usually	49.6	52.4	41.1	51.7	53.1	57.9	74.7	35.4	53.2
% sometimes	23.5	23.3	20.3	24.7	19.4	24.6	16.5	26.9	30.4
% seldom or never	26.9	24.3	38.6	23.6	27.5	17.5	8.8	37.7	16.5
Q21 - If English is not your first language, are there support workers or translators available to speak with you in your preferred language?									
Number of surveys	412	n = 7	65	250	21	18	4	44	10
% always or usually	56.6	58.3	61.5	53.6	61.9	72.2	50.0	59.1	50.0
% sometimes	22.6	24.1	21.5	22.4	23.8	11.1	25.0	25.0	40.0
% seldom or never	20.9	17.5	16.9	24.0	14.3	16.7	25.0	15.9	10.0

Table G - Access & Delivery of Services & Supports: 2002 Data (cont'd)									
STATES	TOTAL AVG.	STATE AVG.	AZ	CA	MA	SC	SD	WA	WY
Q22 - If your child does not speak English or uses a different way to communicate (e.g., sign language), are there enough support workers available who can communicate with him/her?									
Number of surveys	702	n = 7	94	379	63	17	37	68	44
% always or usually	55.0	39.9	42.6	74.4	30.2	58.8	21.6	17.6	34.1
% sometimes	24.8	29.4	35.1	16.4	28.6	0.0	45.9	36.8	43.2
% seldom or never	20.2	30.7	22.3	9.2	41.3	41.2	32.4	45.6	22.7
Q23 - Does your child have access to the special equipment or accommodations that he/she needs (e.g., wheelchair, ramp, communication board)?									
Number of surveys	1,241	n = 7	167	364	176	43	115	249	127
% always or usually	54.7	56.9	57.5	55.5	48.3	60.5	69.6	44.6	62.2
% sometimes	28.9	27.3	25.7	26.1	32.4	16.3	26.1	36.5	28.3
% seldom or never	16.4	15.8	16.8	18.4	19.3	23.3	4.3	18.9	9.4
Q24 - Do you have access to health services for your child?									
Number of surveys	2,273	n = 7	336	674	355	98	171	455	184
% always or usually	88.5	90.4	91.4	81.0	91.3	88.8	96.5	90.3	93.5
% sometimes	7.3	7.0	7.7	8.3	6.5	9.2	3.5	7.5	6.5
% seldom or never	4.2	2.6	0.9	10.7	2.3	2.0	0.0	2.2	0.0
Q25 - Do you have access to dental services for your child?									
Number of surveys	2,337	n = 7	317	780	356	95	159	448	182
% always or usually	85.5	86.7	87.1	83.1	86.8	90.5	88.7	85.5	85.2
% sometimes	6.8	7.2	7.3	6.3	5.9	6.3	8.8	6.9	8.8
% seldom or never	7.7	6.1	5.7	10.6	7.3	3.2	2.5	7.6	6.0
Q26 - Do you have access to necessary medications for your child?									
Number of surveys	2,307	n = 7	316	783	337	97	165	435	174
% always or usually	88.5	90.8	88.0	82.4	91.7	89.7	98.2	91.0	94.3
% sometimes	7.8	6.4	10.4	10.1	5.9	4.1	1.8	6.9	5.7
% seldom or never	3.8	2.8	1.6	7.5	2.4	6.2	0.0	2.1	0.0
Q27 - Are frequent changes in support staff a problem for your family?									
Number of surveys	1,945	n = 7	285	712	251	78	127	328	164
% always or usually	30.8	24.4	24.2	47.3	19.9	25.6	11.8	23.8	18.3
% sometimes	32.2	32.8	34.7	28.2	34.7	25.6	31.5	34.8	40.2
% seldom or never	37.0	42.8	41.1	24.4	45.4	48.7	56.7	41.5	41.5
Q28 - Are support staff generally respectful and courteous?									
Number of surveys	2,109	n = 7	330	713	278	95	159	357	177
% always or usually	79.1	83.5	85.5	64.1	86.3	82.1	93.7	86.6	86.4
% sometimes	15.6	13.2	13.0	23.1	11.9	14.7	5.0	12.3	12.4
% seldom or never	5.3	3.3	1.5	12.8	1.8	3.2	1.3	1.1	1.1

Table H - Choices and Control: 2002 Data									
STATES	TOTAL %	STATE AVG.	AZ	CA	MA	SC	SD	WA	WY
Q29 - Do you choose the agencies or providers that work with your family?									
Number of surveys	2,035	n = 7	313	622	279	85	147	406	183
% always or usually	48.8	51.8	39.6	35.4	53.8	52.9	41.5	61.6	78.1
% sometimes	25.3	24.6	30.7	28.5	24.7	22.4	27.9	19.2	19.1
% seldom or never	25.9	23.5	29.7	36.2	21.5	24.7	30.6	19.2	2.7
Q30 - Do you choose the support workers who work with your family?									
Number of surveys	1,911	n = 7	285	604	268	79	137	358	180
% always or usually	37.0	41.5	31.9	25.2	41.0	46.8	30.7	38.5	76.7
% sometimes	22.1	22.6	24.6	20.4	27.6	21.5	26.3	19.6	18.3
% seldom or never	40.8	35.8	43.5	54.5	31.3	31.6	43.1	41.9	5.0
Q31 - Do you have control and/or input over the hiring and management of your support workers?									
Number of surveys	1,618	n = 7	239	487	224	63	117	331	157
% always or usually	37.4	37.2	26.8	25.5	44.6	28.6	18.8	54.7	61.1
% sometimes	16.9	16.1	16.7	17.5	20.1	12.7	9.4	16.0	20.4
% seldom or never	45.7	46.7	56.5	57.1	35.3	58.7	71.8	29.3	18.5
Q32 - Do you want to have control and/or input over the hiring and management of your support workers?									
Number of surveys	1,589	n = 7	244	450	241	57	111	334	152
% always or usually	60.6	59.1	54.9	55.3	67.2	52.6	43.2	67.4	73.0
% sometimes	23.3	23.4	28.7	25.3	19.5	21.1	29.7	19.2	20.4
% seldom or never	16.3	17.5	16.4	19.3	13.3	26.3	27.0	13.5	6.6
Q33 - Do you know how much money is spent by the MR/DD agency on behalf of your child with a developmental disability?									
Number of surveys	2,355	n = 7	332	800	328	98	162	453	182
% always or usually	22.6	24.6	12.0	14.5	29.6	14.3	22.2	31.1	48.4
% sometimes	9.7	10.1	11.7	6.6	9.1	2.0	16.7	11.9	12.6
% seldom/never/don't know	67.7	65.3	76.2	78.9	61.3	83.7	61.1	57.0	39.0
Q34 - Do you get to decide how this money is spent?									
Number of surveys	1,608	n = 7	211	456	243	55	127	358	158
% always or usually	36.5	37.8	7.6	27.0	53.9	23.6	49.6	39.4	63.3
% sometimes	20.6	20.4	12.8	13.6	21.0	12.7	27.6	31.0	24.1
% seldom or never	42.9	41.8	79.6	59.4	25.1	63.6	22.8	29.6	12.7

Table I - Community Connections: 2002 Data									
STATES	TOTAL %	STATE AVG.	AZ	CA	MA	SC	SD	WA	WY
Q35 - If you want to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports?									
Number of surveys	1,634	n = 7	216	534	243	58	98	347	138
% always or usually	24.7	26.2	26.4	26.6	21.0	34.5	26.5	19.6	29.0
% sometimes	28.0	28.7	26.9	27.3	24.7	22.4	36.7	27.7	35.5
% seldom or never	47.2	45.0	46.8	46.1	54.3	43.1	36.7	52.7	35.5
Q36 - If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?									
Number of surveys	1,617	n = 7	214	505	230	66	113	354	135
% always or usually	33.5	37.5	24.3	32.1	27.4	53.0	52.2	32.5	40.7
% sometimes	24.1	23.1	22.4	24.6	22.6	18.2	24.8	27.1	22.2
% seldom or never	42.4	39.4	53.3	43.4	50.0	28.8	23.0	40.4	37.0
Q37 - Do you feel that your child has access to community activities?									
Number of surveys	2,149	n = 7	286	670	347	88	154	426	178
% always or usually	31.1	33.6	40.6	30.7	21.6	47.7	30.5	27.2	37.1
% sometimes	40.3	39.9	37.1	38.2	43.5	29.5	42.9	41.5	46.6
% seldom or never	28.7	26.4	22.4	31.0	34.9	22.7	26.6	31.2	16.3
Q38 - Does your child participate in community activities?									
Number of surveys	2,195	n = 7	304	677	359	88	154	435	178
% always or usually	19.5	20.3	23.7	19.2	18.4	23.9	16.9	16.8	23.0
% sometimes	38.9	39.3	35.2	37.7	35.7	34.1	40.3	41.8	50.0
% seldom or never	41.6	40.5	41.1	43.1	46.0	42.0	42.9	41.4	27.0
Q39 - Does your child spend time with children who do not have developmental disabilities?									
Number of surveys	2,327	n = 6	339	814	360	* Question not asked	166	464	184
% always or usually	51.7	52.3	63.1	52.6	41.9		57.2	47.6	51.1
% sometimes	34.8	34.8	28.3	33.9	39.4		31.9	37.5	37.5
% seldom or never	13.5	13.0	8.6	13.5	18.6		10.8	14.9	11.4

Table J - Satisfaction with Services and Outcomes: 2002 Data									
STATES	TOTAL %	STATE AVG.	AZ	CA	MA	SC	SD	WA	WY
Q40 - Overall, are you satisfied with the services and supports your child and family currently receive?									
Number of surveys	2,375	n = 7	336	811	331	91	167	456	183
% always or usually	56.5	60.5	62.2	56.5	41.4	65.9	82.6	47.6	67.2
% sometimes	34.7	32.1	33.6	33.5	40.8	27.5	16.2	43.4	29.5
% seldom or never	8.8	7.4	4.2	10.0	17.8	6.6	1.2	9.0	3.3
Q41 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?									
Number of surveys	2,261	n = 7	316	789	316	79	157	424	180
% always or usually	36.8	36.9	42.1	40.4	28.8	31.6	43.9	26.9	44.4
% sometimes	11.9	12.0	9.2	15.2	5.7	19.0	12.1	10.8	11.7
% seldom/never/don't know	51.4	51.2	48.7	44.4	65.5	49.4	43.9	62.3	43.9
Q42 - Are you satisfied with the way complaints/grievances are handled and resolved?									
Number of surveys	834	n = 7	119	328	76	46	52	150	63
% always or usually	49.9	51.8	50.4	49.4	47.4	54.3	65.4	44.7	50.8
% sometimes	31.4	30.0	29.4	33.2	28.9	26.1	25.0	32.7	34.9
% seldom or never	18.7	18.2	20.2	17.4	23.7	19.6	9.6	22.7	14.3
Q43 - Do you feel that family supports have made a positive difference in the life of your family?									
Number of surveys	2,211	n = 7	306	713	319	91	167	438	177
% always or usually	65.7	69.4	67.0	59.9	56.4	71.4	92.2	67.1	71.8
% sometimes	26.4	23.8	27.8	30.9	29.8	20.9	7.2	24.7	25.4
% seldom or never	7.9	6.8	5.2	9.3	13.8	7.7	0.6	8.2	2.8
Q44 - Do you feel that family supports have improved your ability to care for your child?									
Number of surveys	2,211	n = 7	305	716	317	88	166	442	177
% always or usually	63.7	67.0	67.9	58.2	54.3	64.8	89.2	63.8	70.6
% sometimes	26.3	24.1	23.9	31.4	27.8	26.1	7.8	25.6	26.0
% seldom or never	10.0	8.9	8.2	10.3	18.0	9.1	3.0	10.6	3.4
Q45 - Do you feel that family supports have helped you to keep your child at home?									
Number of surveys	1,953	n = 7	253	654	269	77	146	392	162
% always or usually	69.1	72.5	73.1	64.2	61.7	77.9	83.6	69.1	77.8
% sometimes	16.6	15.4	15.8	19.7	14.5	11.7	10.3	15.1	20.4
% seldom or never	14.3	12.2	11.1	16.1	23.8	10.4	6.2	15.8	1.9
Q46 - Overall, do you feel that your child is happy?									
Number of surveys	2,440	n = 7	338	832	356	92	170	469	183
% always or usually	81.4	83.5	86.4	78.2	78.7	87.0	88.2	80.0	86.3
% sometimes	16.9	15.0	12.7	19.6	18.0	10.9	11.8	18.8	13.1
% seldom or never	1.7	1.5	0.9	2.2	3.4	2.2	0.0	1.3	0.5